



UNIVERSITY  
OF TASMANIA

**Understanding the bioecological determinants of  
vascular access for haemodialysis therapy. A case  
study in one satellite haemodialysis community.**

By

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## STATEMENT AND DECLARATIONS

### Declaration of Originality

“This dissertation contains no material which has been accepted for a degree or diploma by the University or any other institution, except by way of background information and duly acknowledged in the dissertation, and to the best of my knowledge and belief no material previously published or written by another person except where due acknowledgement is made in the text of the dissertation, nor does the dissertation contain any material that infringes copyright.”

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Clinical Case Reports:

‘Maintaining a viable vascular access for haemodialysis in an elderly person with diabetes: A journey to live, not just to stay alive.’ is located in Chapter two.

Debi Cowan as the Higher Degree Candidate was the primary author and as I am author 2 as the primary supervisor for the candidate’s dissertation and Josephine Chow as the candidate’s second supervisor and as author 3 have contributed to the ideas for this paper, formalisation and development as outlined here and or in the publication.

Journal of Renal Care:

‘Care of a patient’s vascular access for haemodialysis: A narrative literature review. Journal of Renal Care’ is located in Chapter three.

Debi Cowan as the Higher Degree Candidate was the primary author and as I am author 2 as the primary supervisor for the candidate’s dissertation and Josephine Chow as the candidate’s second supervisor and as author 3 have contributed to the ideas for this paper, formalisation and development as outlined in the publication.

Australian Nursing and Midwifery Journal:

‘Understanding the journey travelled by patients and carers living with end stage kidney disease and haemodialysis.’ is located in Appendix 2.

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## **ABSTRACT**

This research project utilised a case study methodology to investigate the bioecological factors influencing the management and care of patients with a vascular access (VA) for their haemodialysis therapy. In Australia in 2012, 61% of patients receiving haemodialysis therapy were treated by a satellite haemodialysis unit (SHDU) (ANZDATA 2013). The boundary for this single case study was one SHDU in Australia and the people associated with this community. This included people living with ESKD receiving a regimen of haemodialysis therapy, those who care for or have an interest in the care of the patient and their VA, their family and or friends as carers and healthcare professionals in the SHDU during the period of data collection. The bioecological model of process, person, context and time (PPCT) (Bronfenbrenner & Ceci, 1994) was used throughout the case study to guide the research method, analysis and presentation of results.

The case study report commences with the articulation of the descriptive theory – the articulation of what is known about the phenomenon (Tobin, 2010, pg. 288). This descriptive theory utilised an emic perspective to embed the researcher into the parameters of the case and included three works of scholarship. Firstly a narrative literature review was undertaken with the aim to explore the current understanding of what factors influence the care of patients with a VA for haemodialysis. The narrative review revealed five themes related to care of a patient's VA: patient's experience; relationships-empowerment and shared decision making; environment of healthcare; time; quality of life as the outcome of care. Secondly, a reflection on past clinical practice using a single person case study approach was completed. Thirdly, a review of the journey typically travelled by a

person with ESKD and their family and friends as carers was documented by the researcher drawing on clinical experience as a nephrology (renal) haemodialysis nurse and current available literature.

This case study collected data through a self-administered questionnaire comprising of open ended questions that varied between the participant groups and Likert scale questions for the patient participants of a range of pertinent variables identified through the descriptive theory. These included physical and mental wellbeing as measured by the SF-36v2® (physical health component and mental health component), empowerment, family strengths and the SHDU ecology. The questionnaires were completed by 32 patients, 8 family or friends as carers and 14 healthcare professionals anonymously.

The mixed methods case study findings demonstrated that the outcomes of managing a patient's VA is influenced by everyone in the ecology of care – the patients, their family and or friends as carers and healthcare professionals. Subsequently, significant and previously unexplored relationships between the three participant groups within the SHDU community emerged. Arising from this research is the recommendation that clinical practice guidelines which concentrate on the biological factors of nursing care should be supported by bioecological domains.



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## **GOSSARY AND ACRONYMS**

### **AVF**

Represents the patient's autonomous 'arterio-venous fistula' which is surgically created by anastomosing a vein to an artery general within the patients upper limbs (Feddersen & Roger 2012) to allow access to the patient's cardiovascular system obtaining rapid blood flows by utilising two wide bore cannulas for the patients haemodialysis therapy regimen. One cannula is for the removal of blood through the continuing circuit and the second cannula is to return the patient's blood to their body, usually during a period of time of four to six hours and generally this routine is three days per week.

### **AVG**

Indicates a patient's 'arterio-venous graft' which is generally a synthetic conduit utilised to form a conduit-fistula. AVGs are predominantly composed of plastic polymers (Jennings et al. 2011). As a conduit, a synthetic length of tubing is anastomosed one end to the patient's artery and the alternative end is anastomosed to the patient's vein. Generally an AVG is placed subdermal, in any of the patient's limbs and again require cannulation as their vascular access. Similarly to AVFs the patient's AVG is cannulated to gain access to rapid blood flows for their haemodialysis therapy regimen.

### **CKD**

Utilised throughout this dissertation as representing the five stages of a patient's declining kidney function known as 'chronic kidney disease' (Pagels et al. 2015).

## **CS**

Represents 'case study' research, which is the methodology chosen for this project for the investigation of this particular phenomenon to provide a holistic approach to this case (Gillham 2000).

## **DCVC**

Represents a patient's designated 'haemodialysis central venous catheter' (Lopez-Vargas et al. 2011). Generally this would be a tunnelled and cuffed DCVC, which is customarily inserted into the patient's right internal jugular vein (chest) (Polkinghorne et al. 2013) and is positioned with the tip of the double lumen catheter placed in the right atrium of the patient's heart guided by ultrasound fluoroscopy to ensure correct placement of the catheter tip. A patient's DCVC may remain as a semi-permanent or in some cases a permanent access to the patient's cardiovascular system. Thus, allowing for the continuous access to rapid blood flow rates, for their haemodialysis therapy treatment regimens.

## **ESKD**

Represents 'end stage kidney disease' which is the final stage of a patient's kidney disease. The patient may follow a pathway of conservative medical care until their demise (Josland et al. 2012), or alternatively they may have the opportunity to choose between options of receiving a kidney (renal) transplant and or modes of dialysis treatments to replace some level of their kidneys' responsibilities (Chanouzas et al. 2012), in order to continue their survival optimally over a longer period of time.

## **QOL**

Represents 'quality of life'. The concept of QOL is broad and complex and it is very personal, being the individual's perception of how they see their position in life in the

context of both culture and value systems at that point in time (World Health Organization (WHOQOL 1997)).

## **RRT**

Represents options for 'renal replacement therapy' once the patient reaches ESKD, patients may receive a kidney transplant and or modes of dialysis therapy of peritoneal dialysis, or haemodialysis which requires a viable vascular access (Feddersen & Roger 2012).

## **VA**

Refers to a patient's haemodialysis 'vascular access'. This can be a semi or permanent vascular access to rapid blood flows within the patient's cardiovascular system. This allows blood to be drawn by a pump, generally at speeds of 300 to 350 mills per minute through a closed circuit of tubing connected to an artificial kidney referred to as a dialyser (Ronco & Levin 2004). Therefore it is imperative to achieve a viable VA for the patient, to continue treatments for an effective haemodialysis therapy regimen.

## **Wellbeing**

Wellbeing has been defined as 'achievement of a good and satisfactory existence as defined by the individual' (Harris et al. 2005, p. 1827). For the purposes of this research, wellbeing as a concept was used in the open ended questions without providing a definition. A shared definition between the researcher and the participant was not attempted in this research project. Instead the participants were asked to express their own thoughts on how they achieved wellbeing, whatever that may mean to them. Quality of life is a commonly utilised outcome indicator of wellbeing from a strengths perspective.

# **CHAPTER ONE: THE OVERVIEW OF THIS CASE STUDY**

## **Introduction**

This case study will examine the bioecological influences on achieving and maintaining a viable vascular access (VA) for the patient living with end stage kidney disease (ESKD). The care of the patient's VA is the responsibility of everyone involved and with an interest in the care of the patient (Feddersen & Roger 2012). This includes the team's healthcare professionals, the patient and family and or friends as their carers (family/carers).

This chapter will firstly provide a brief summary of the research project including the research aim, and question and method. This will be followed by an overview of the theory underpinning this research, the Bioecological Theory of Human Development. The chapter will conclude with an overview of the subsequent chapters in this dissertation.

## **The aim of this study**

To understand the role and influences of nursing care that supports patients and family/carers to maintain the viability of the patient's vascular access in a satellite haemodialysis community.

## **Research question**

What bioecological factors influence the outcome of care of patients' vascular access for haemodialysis treatment?

## **Research method**

This research project utilised a case study method to explore the bioecology of a single centre satellite haemodialysis unit (SHDU) community. The SHDU community included in this research project were the patients, their family/carers and the health care professional staff. The phenomena of interest, was the patient's vascular access care, as expanded and discussed in Chapter Four.

## **Context and Significance of this study**

The context of the study is articulated in the descriptive theory presented in Chapters Two, Three and Appendix 2 'Understanding the journey travelled by patients and carers living with end stage kidney disease and haemodialysis'. In case study research, 'the articulation of what is already known about the phenomenon is called a descriptive theory' (Tobin 2010). See Chapter Four, p. 44 for further details on a descriptive theory. Included within the articulation of the descriptive theory for this case study is the detailed context of this study. Secondly, included within the conclusion of the descriptive theory for this case study is of the significance of this study. To orientate the reader, this section now presents an overview of the descriptive theory found within the subsequent chapters.

People experiencing end stage kidney disease (ESKD) are dependent upon the viability of their vascular access (VA) to enable them to achieve a continual regimen of effective haemodialysis therapies. There is a prevalence of chronic diseases including ESKD that are expected to continue to rise due to extended life expectancy. Already this has been shown to result in frailer elderly populations through



progressing stages of chronic kidney disease (CKD) (Abdelhafiz et al. 2013).

Importantly, elderly patients generally have fewer and less viable options for their VAs, frequently attributed to the patient's peripheral and cardio-vascular disease.

Therefore it is understandable that patients VAs require a regimen of rigorous monitoring and care which includes the patient self protecting their VA.

### **Context of the study**

By the end of 2011, global population had reached 7 billion which included 2,786,000 people living with ESKD and undertaking renal replacement therapies (RRT)(Fresenius Global Services 2011). In Australia by 2012, there were 9219 people living with ESKD and undertaking haemodialysis therapy, an increase of 3% from 2011 with 51% of these patients aged 65 years and older having included 27% of this population aged 75 years and older (ANZDATA 2013). Patients who are living with ESKD remain dependent on medical care. The majority of patients in Australia living with ESKD in 2012 received their haemodialysis therapy and care within satellite haemodialysis unit (SHDU) communities (ANZDATA 2013).

People living with ESKD, experience chronicity along with co-morbidities of the disease process and the complexity of living with treatment regimens and regular time consuming medical appointments (Moist et al. 2008). The decline-loss of patients' renal function can be closely aligned with reduced cognitive function-dementia (MacPhail et al. 2012). Diabetes and peripheral-cardio vascular disease are common co-morbidities among this population, with approximately 50% of patients dying before reaching ESKD (Cho et al. 2012). For patients who progress to ESKD, finding a viable option for their VA and maintaining the longevity of their VA in order to

enable these patients to receive an effective regimen of haemodialysis therapies can be problematic as demonstrated in Chapter Two. The most frequent complications patients experience are thrombosis and infection of their VAs and septicaemia (Feddersen and Roger 2012). These complications often result in loss of a patient's VA, directly align to increased risk to patients' morbidity or mortality and increased cost of the care to patient, their family, the community and healthcare services (Sgroi et al., 2013).

Research comparing RRT options of peritoneal dialysis and haemodialysis modalities overall patients have similar survival rates (Moist 2014). Likewise studies comparing VAs of native arterio-venous fistula (AVF), synthetic arterio-venous graft (AVG) and haemodialysis central venous catheters (DCVC) have shown all options can result in the patient experiencing complications (Moist 2014). Patients who have AVGs and DCVC however, are placed at an increased risk of complications hence morbidity and reduced survival rates of their VA (Feddersen and Roger 2012). For example DCVCs have resulted in higher risks to the patient of fatal infections and cardiovascular events compared to AVFs (Moist 2014).

Renal replacement therapy and VA has an associated reduced QOL and increased risk of co-morbidities and mortality. For example patients who rely on DCVCs as their VA carry the highest risk of complications including thrombosis, infection and reduced efficiency of removal of toxins and wastes from their body (Polkinghorne et al., 2013, Feddersen & Roger, 2012, Bessias et al., 2008). This group of patients are 2-3 times more likely to be hospitalized due to infection, stay

longer in hospital and die from septicaemia when compared to patients with AVFs (Moist 2014).

Patients may experience multiple VA related problems requiring revision, revival or replacement of their vascular access. Peripheral-cardio vascular disease increases the frequency of VA complications and the person requiring a VA, may become devoid of any permanent vascular access options to enable them to continue receiving haemodialysis therapy. Maintaining the viability of a person's VA is an important outcome of nursing care (Moist et al. 2013; Schmidt et al. 2012; Wang et al. 2008).

### **The significance of this study**

A person living with chronic kidney disease (CKD) or progressing to ESKD frequently experience co-morbidities such as diabetes, peripheral cardio-vascular disease and loss of cognitive function. As demonstrated, patients can experience the chronicity of the disease of symptom burdens and complex treatment regimens as revealed in Chapter Two, Chapter Three and Appendix 2 'Understanding the journey travelled by patients and carers living with end stage kidney disease and haemodialysis.'

Together renal nurses in their clinical roles and in specialised roles of renal VA coordinators, renal nurse practitioners and that of supportive care renal nurses can support a patient's physical and psychological needs. Importantly, patients and their family/carers wishes can be addressed by nurses and incorporated into care planning, key objectives to improve patients and their family/carers quality of life, as demonstrated in Chapter Two by addressing the patient's wishes to live and not just stay alive.

Persons living with CKD or in reaching ESKD have diverse clinical needs. Appendix 2 'Understanding the journey travelled by patients and carers living with end stage kidney disease and haemodialysis' reports a typical journey that patients and family/carers travel. The care of a patient's VA can involve many people who have an interest in the patient's care, including their family and carers alongside the healthcare team (Feddersen & Roger 2012). A shared-care approach to VA care through a lens of the bioecological model has not been explored to date in the literature.

### **Theoretical background: The bioecological theory of human development.**

The Theory of Human Ecology was initially proposed as a theoretical model of human development in the 1970's by Bronfenbrenner (Bronfenbrenner 1979).

Bronfenbrenner's theory of human development continued to evolve until his death in 2005 (Tudge et al. 2009). As such the final theory, The Bioecological Model of Human Development (Bronfenbrenner 2001) was developed over a period of more than 30 years (Arnold et al. 2012). The initial phase of ecological systems theory was one that focuses on the interrelations of the individual-environment. The second phase during the 1980s, emphasised greater attention was devoted to the role of the individual and their developmental processes. During the third phase from 1993, Bronfenbrenner had begun focussing on the "proximal processes" being the engines of human development and by 1998 these elements had become the heart of Bronfenbrenner bioecological theory (Rosa & Tudge 2013).

The Bioecological Theory of Human Development is illustrated in the process-person-context-time (PPCT) model, and is the most mature development of Bronfenbrenner's human ecology theory. In the description of the PPCT model, Bronfenbrenner considered the reciprocal influences of the environmental systems on the person as well as the person's influence on the environmental system, with an ecological emphasis on person-context (models) exploring interrelationships (Rosa & Tudge 2013) (see Appendix 1. 'The bioecological model').

All theories travel through their own evolution (Tudge et al. 2009) and fortunately for scientists/researchers, Bronfenbrenner was particularly transparent in his work developing his own theories, which has enabled investigators to follow carefully any particular phase of Bronfenbrenner's human development theory. The PPCT model had been the fruit of an entire lifetime of Bronfenbrenner's work into understanding a human's development. Bronfenbrenner himself identified that his PPCT model would be the most appropriate research design to be utilised by human development scientists (Rosa & Tudge 2013). Consequently the PPCT model had become the essence of Bronfenbrenner's theory of human development (Tudge et al. 2009).

Understanding human development underwent significant advances in Bronfenbrenner's theory over other models as it examines the 'holistic integration of interpersonal relationships with larger societal, cultural and political forces in the developmental processes.' (Smith, L 2011a, p. 2).

## **The ecology of human development: The original theory.**

Bronfenbrenner's original Ecology of Human Development is commonly utilised in human and applied health research, depicting the individual in the centre of Bronfenbrenner's four ecological systems as "layers" in order to conceptualise environmental contexts (Darling 2007). These four layers represent the levels which are nested together and which organise the person's social ecology in their development (Weisner 2008) (see Appendix 1. 'The bioecological model' (Howe 2011)).

The ecological systems begin with the microsystem, the innermost layer which comprises of the person's interpersonal relationships e.g. their family and their direct interactions with their surroundings. It is within the microsystem that all levels of environmental influences are filtered, where an individual's experiences actually take place (Arnold et al. 2012). The second layer, the mesosystem is a crucial layer depicting interactions. Networks, connect and overlap across the microsystem e.g. relationships, objects, messages as the symbols of a person's everyday world (Arnold et al. 2012). The third layer, the exosystem symbolises a level in one's environment, where events occur that may indirectly impact on processes that occur within a person's immediate setting. Exosystems are not physically present in the person's environment e.g. the place of work of a child's parents can have an indirect effect on their child, such as the parent's hours of work and pay. The fourth layer is the macrosystem and as the broadest level represents ideology, culture, major social institutions e.g. religion, government and social economy (Arnold et al. 2012), education and legal (Rosa and Tudge 2013). The ecological model is contained

within the Bioecological model as it can be considered to represent the 'context' domain of the PPCT model.

The macrosystem envelopes the levels as it influences and is influenced by all the systems (Tudge et al. 2009). All other levels of ecology exist within the macrosystem which can and do change as a result of pressures that are exerted from other levels of the environment and do so as a function over time. Time being the final part of Bronfenbrenner's PPCT model depicted as the chronosystem, affects all levels of the environment and in the ways that individuals interact with their ecosystem. Chronosystem includes the timing of a person's transitions in life e.g. a student's progression as a pathway of a longitudinal process of orderly steps and timing. Chronosystem also distinguishes the effects of changing social contexts within historical time (Arnold et al. 2012). As exemplified by patient's experiencing transition over time, of living through stages of increasing kidney dysfunction referred to as chronic kidney disease (CKD) (Pagels et al. 2015) resulting in end stage kidney disease (ESKD). At which stage, the individual requires a regimen of treatments in order to prolong one's survival by replacing some degree of their kidney function. Patients are compelled to invest considerable amounts of time attending hospital appointments, modalities of renal replacement therapy (RRT) such as haemodialysis therapy and managing their medications, dietary and fluid restrictions (Bonner et al. 2010).

### **The bioecology of human development: The refined theory**

As a self-reflective theorist, Bronfenbrenner frequently noted the transforming nature of his theory. Aware other key factors were being missed while he had been

focussing too intently on the context of their development e.g. the environment, he had overlooked the individual's own role that played in his or her own development (Tudge et al. 2009). It was during the 1990s Bronfenbrenner had added Chronosystem while contemplating the role of "time" in one's development. By observing the processes and the biological person, paying attention to the proximal processes exploring how the person along with their environments can change over time (Rosa & Tudge 2013). Proximal processes essentially represent patterns of interactions of person-environment in the microsystem (Arnold et al. 2012). Rosa and Tudge (2013) point out human development is a progressive change in the individual's characteristics over both time and space, signifying a continuity of both the individual and the environment.

The proximal processes of human development, take place through processes of more and more complex reciprocal interactions. Hence, over prolonged periods of time alongside enduring forms of regular interactions as an active biopsychological human organism gains from the people, entities and symbols which make up the person's direct environment (Bronfenbrenner & Morris 1998). Bronfenbrenner had focussed on the individual's role in their own development as had he began to afford explicit consideration to the passage of time, during a person's development (Rosa & Tudge 2013).

The individual can produce their own development, acting on the context of the environment and in the same way these interactions are reciprocal as the environment reacts on the individual (Arnold et al. 2012). As such the PPCT model highlights the importance of understanding the dynamic bidirectional interactions



between the person and other individuals and their ecology (Smith, L 2011a). The individual's characteristics, in conjunction with the elements of the context, both spatial and temporal can influence proximal processes over lengthy periods of time (Rosa & Tudge 2013).

Human ecology theories retain the assumption that a person and their environments are inseparably intertwined and that human development transpires as they transform toward progressively more complex interactions and hence the person is able to adequately function in their environments. Negative personal outcomes however, have shown a strong relationship of individuals and environmental disorder and dysfunction. Which had the effect, later in his life to steer Bronfenbrenner to retitle his theory, as bioecological and not ecological as he endeavoured to signify that an individual's developmental processes can either encourage or inhibit their personal potential (Arnold et al. 2012). Caring relationships are a critical element to the developing individual, not only in among their family, but in all settings the individual occupies (Damon & Lerner 2006).

Bronfenbrenner argued that many scientists did not take into account that an individual's development was a process of continuity and change which occurs over a lifetime from a cause of events and experiences (Rosa & Tudge 2013). Rosa and Tudge (2013) point out such experiences can stem from the external environment or from within the individual. Such changes can be normative i.e. being expected such as starting school or non-normative being unexpected such as a sudden death or illness within the family. To understand human development at any stage in an individual's life journey, it is important to understand the individual's choices both

before and after events happen, which influence the individual's life (Rosa & Tudge 2013) in order to understand these changes.

## **Utility of PPCT model to a case study research and patients living with ESKD**

The Bioecological Theory of Human Development is an applicable model to guide this case study (CS) research project. The theory can be related to the patients' experience of living with ESKD, by guiding the research method and assist the analysis of the data. Patients and their family/carers included in this CS experience living through stages of declining kidney function of CKD and living with ESKD requiring RRT. Changes happen throughout an individual's life course, and in which historical era the person has lived. Changes come into play through the environment's influence on the individual and just as significantly the reciprocal influence of the individual on their immediate environment, indicated as a 'person-environment interaction' (Weisner 2008, p. 261). Bronfenbrenner through his Bioecological Theory of Human Development i.e. PPCT model 'explains the drivers of human development as the interactions that occur between an individual (their biological being) and the interconnecting systems surrounding them (their ecology)' (Smith, L 2011a, p. 2). The Bioecological Theory of Human Development was the theoretical model underpinning this research. The application of the theoretical underpinning in this dissertation was as follows.

Chapter Two reports the journey of one person and her family living with ESKD and repeated attempts to gain a viable VA. The case study explores the proximal processes, the context and the journey over time period of 4.5 years.

Chapter Three utilised the bioecological model to guide the thematic analysis of the narrative literature review. The four key factors of person, process, context and time aided the identification of five themes related to care of a patient's VA: patient experience; relationships-empowerment and shared decision making; environment of healthcare; time; and quality of life as the outcome of care.

Chapter Five presents the results from the first two phases of Braun & Clarke's (2006) six phases of thematic analysis. The PPCT model was instrumental to collate key words within the data into 13 concepts. (See full table of results of the content analysis in Appendix 13 'PPCT model: 13 Concepts, texts and terms employed by each group').

Chapter Six presents the thematic analysis results with seven key themes representative of the four concepts of the PPCT model. Process was represented by the themes developing a positive perspective and empowerment. Person was represented by the themes patient comfort and VA. Context was represented by the themes safe and friendly environment and support systems. Time was represented by the theme patient's and or carers' QOL and wellbeing. Utilising the PPCT model promoted an understanding of the research participant (the patient, carer/family and healthcare professional) as an 'active person enmeshed in an active, dynamic, social-ecological system' (Weisner 2008, p. 258).

Chapter Seven engages the PPCT model as a framework for discussing the results of the CS and reconceptualises the quintain as six statements.

Throughout this research the person (patient's, family/cares, healthcare professional) and the proximal process between them occurring in a specific context of nursing care over time is explored.

The PPCT model provided a valuable analytic process based on exploring frequency, saliency and nature of participant responses to the open ended questions. The PPCT model offered a framework which tied the research findings together in meaningful ways.

## **The continuing story**

This research project contained an emic perspective embedded within this CS. The emic view will be evident under the reoccurring section titled 'The continuing story'. The emic perspective is also legitimised through the descriptive theory presented in the CS. An emic view in the nursing profession is best defined as having an insider perspective (Ng'ang'a et al. 2014).

My position as a researcher within the (renal nursing field) is founded on my clinical experience as a nephrology (renal) nurse over a thirty seven year period of time. During this time, I have continued to develop my knowledge and skills to advance my care of patients living with CKD-ESKD, as exemplified by my completion of a Nephrology and Transplant Certificate, Diploma in Nursing (Renal Stream) and Master of Clinical Nursing (Renal Stream). The emic perspective contained within 'The continuing story' has been drawn from reflective journaling.

I utilise a process of self-reflection, which I drew from my experiences to advance my ability to holistically care for patients and their families and friends, within the complex healthcare environments of our community's renal healthcare services. I have utilised reflective journaling, to develop my personal (emotional wellbeing) and professional expert clinical skills as a "reflection in action" (Brathovde et al. 2013). Similarly, I have made use of reflective journaling throughout this CS project. As explained further on p. 74, CSs are not impeded through their restriction to any particular paradigm of research (Keyzer 2000). Therefore a research method of reflective journaling has been effectively utilised throughout this dissertation to gain

greater understandings of the information afforded by the participants' responses, to the research questionnaires.

In my own experience over the last 37 years of caring for patients as a renal nurse, I have seen that people in general who have not been physically and or emotionally affected by CKD-ESKD and therefore have a need to make critical healthcare choices, have very little understanding of this journey. In many cases patients and loved ones, are afforded little choice between supportive (conservative) care and or RRT options and treatments and therefore, generally people have scarce or no knowledge of what the patient and their family and friends as loved ones, might experience during this course of their life journey. 'The continuing story' is located at the end of each chapter prior to the introduction to the subsequent chapter.

Chapter two, Chapter three and Appendix 2. 'Understanding the journey travelled by patients and carers living with end stage kidney disease and haemodialysis', will form the descriptive theory for this CS. The utility of a CS strategy is in 'the articulation of what is already known about the phenomenon, called *descriptive theory* (Tobin 2010, p. 288). Descriptive theory retained dual functions during this investigation. In brief it was employed to review the theoretical underpinnings of this CS, by reviewing relevant literature to the case and in presenting the context of the case (Smith, L 2011b). In the early preliminary stage of utilisation of a CS, it is important that the investigator understands the theory context, as this provides the CS's theory-driven bases of the subsequent analysis and theory development. This dissertation presents three journal articles which have been written to provide a clear understanding of the descriptive theory.

## **The structure of the dissertation**

Chapter two presents an article from the patient's experience and researcher's emic perspective 'Maintaining a vascular access for haemodialysis in an elderly person with diabetes: A journey to live, not just to stay alive'. (see Appendix 4. 'Publications and presentations during candidature.'). As the student researcher, I entered this research as an experienced renal nurse and Chapter Two provides an account of a case that I had personally nursed from the early stages of this research project. An emic perspective is also articulated in Appendix 2., as 'Understanding the journey travelled by patients and carers living with end stage kidney disease and haemodialysis.' which provides a brief understanding of a patient's and their family's journey living with ESKD drawn from both clinical experience and evidence in the available literature (see Appendix 2. 'Understanding the journey travelled by patients and carers living with end stage kidney disease and haemodialysis.').

Chapter Three presents the outcomes of a narrative review of the literature conducted in the beginning of this research project titled 'Care of a patient's vascular assess for haemodialysis: A narrative literature review.' The literature review utilised the bioecological model to guide the thematic analysis of current literature. The aim of the narrative literature review was to explore the current understanding of what factors influence the care of a patient's VA for haemodialysis. Utilising a narrative literature review allowed for the synthesis of the known literature pertinent to the research question into a succinct model or unique order to enable new understandings to emerge. The bioecological model was used to guide the thematic analysis of the literature which revealed five themes related to care of a VA: patient

experience; relationships-empowerment and shared decision making; environment of healthcare; time; and quality of life as the outcome of care.

Chapter Four presents the CS methodology and CS method utilised to investigate the bioecology of the patients and their VA care. This chapter discusses the CS methodology and CS method, and why a case study methodology will inform practice through its findings. A CS offered the most appropriate strategy for this investigation, as it focussed on a contemporary phenomenon within the real-life context. Therefore, a CS would provide a more in-depth understanding from a holistic perspective of 'what lies behind the more subjective evidence' (Gillham 2000, p. 7).

Chapter Five will present the case and the purpose of this study, the analytic processes of the case's qualitative data content analysis, while Chapter Six will follow with the thematic analysis and quantitative analysis. Both chapters follow Braun and Clarke's, (2006) six phases of thematic analysis with a minor component of quantitative analysis. Phase one of the content analysis had included collating data and familiarising oneself and recording potential coding of the data. Phase two was a process of systematically rechecking and coding data, an ongoing process where the coding of data became thirteen concepts.

Chapter Six the thematic analysis, continues Braun and Clarke's (2006) phases of thematic analysis by moving into the third phase of searching for themes. The forth phase included reviewing these themes. The fifth phase was a process of defining and assessing if the themes represented the data and the sixth phase was producing the report of this thematic analysis. As described in this chapter a minor quantitative analysis allowed for the triangulation convergence of the study's results.



Chapter Seven will present the discussion that follows the pattern of reporting findings related to the quintain advocated by Stake (2005), who considers it is important for a CS report to show how the quintain is newly conceptualised as a result of the study.

Chapter Eight presents the conclusion of this CS with recommendations arising from this study in order to optimise patient and family/carer outcomes of care.

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## **CHAPTER TWO: A CASE REVIEW**

### **Introduction**

The following case study (CS) is of one patient, who I had personally nursed from the early stages of this research project. The CS reports the journey of one patient living with ESKD and requiring a viable VA for effective haemodialysis therapy. Through retaining active participation, including both the patient and her family they were enabled to make informed choices about the patient's healthcare options. The journey included a series of attempts to create a mature and viable VA for this patient as I articulate my own emic perspective of the patient's journey. The patient and her family strived for the patient to experience longevity and a life worth living.

The article demonstrates the medicalisation of the patient and family journey. Documenting the CS elucidated the patient's and her family's experience. The CS initially presents a bio-medical approach to maintaining a patient's VA. Medical procedures may assume precedence and direct patient and family's/carers' journeys when living with CKD-ESKD. The CS however, moved to contextualise the care and present the complex ecology of the patient and her family's experience of living with ESKD. Enlightened by this CS is the relationship within the ecology of healthcare. Effective relationships in healthcare are based on healthcare professionals, patients and families/carers working as partners (Barnes et al. 2013). Renal nurses have diverse roles that support patients and their families and friends. As an example, when patients living with CKD receive an early prognosis renal nurses can provide timely support and education helping the patient and their family/carers to make

informed decisions. Patient outcomes may be enhanced when the expectations of all parties involved in or with an interest in the patient's care support the patient to be engaged in their healthcare (Washington 2013). Educating patients in regards to healthcare options can be a key to attaining an increased responsibility in their health care (Bennett and Neil 2008). In this case, maintaining viability of the patient's VA enhanced the patient and her family's QOL. Elements of a family nursing perspective are revealed in this CS that demonstrate the holistic role of the renal nurse, supporting the patient and family through endorsement of the patient's goal to live not just merely to stay alive.

This CS has been synthesized into a journal article, which has been published by the Clinical Case Reports journal available online December 2015. The online (open access) version of this article is embedded into this dissertation as Chapter two and preserves the submitted format. The article is available as the following reference:

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# **Maintaining a viable vascular access for haemodialysis in an elderly person with diabetes: A journey to live, not just to stay alive.**

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## **Key clinical message**

The longevity of a successful vascular access (VA) is enhanced when the care of the patient's VA is the responsibility of everyone involved, including the patient and their family. A family nursing perspective enhances VA care outcomes and increases quality of life and wellbeing for patients requiring haemodialysis.

## **Key words**

Diabetes, End stage kidney disease, Haemodialysis, Vascular access, Quality of life, Family nursing

## **Introduction**

The case presented is of a 70 year old Australian Caucasian woman with Type 2 insulin-dependent diabetes receiving a regular schedule of haemodialysis therapy for end stage kidney disease (ESKD). We follow the journey of one person's care where the patient and her family's goal is to connect deeply with each other while maintaining the patient's quality of life (QOL) and wellbeing. The active engagement of the family in the care and decision making process detailed in this case is atypical. Not every client has a proximal family with functional bidirectional relationships however this case illustrates, the importance of including the family or an external personal carer in healthcare.

Elderly patients receiving peritoneal dialysis or haemodialysis as their renal replacement therapy (RRT), frequently remain reliant on this mode of RRT without release from their dialysis schedules through receiving a kidney transplant. This is commonly owing to a lack of donor organs available for kidney transplantation (Feddersen & Roger, 2012). This patient however was ineligible to receive a donor kidney because of the physiological effects of chronic kidney disease (CKD) and additional co-morbidities. Unlike this case study, many elderly patients with ESKD accept a conservative or supportive care pathway that does not involve modalities of RRT (Josland et al., 2012).

## **Case History**

The patient's medical history included gestational diabetes during her second pregnancy at age 36 continuing onto Type 2 insulin-dependent diabetes. For the ensuing 30 years, diabetes became the underlying root cause of the patient's CKD.

Both diabetes and CKD have resulted in extensive vascular disease leaving the patient's healthcare, including the nephrologist and vascular surgeons, with the dilemma for establishing the most likely options for viable VA in readiness for when the patient reached ESKD. Pathophysiology considerations included the patient's arterial vascular disease which includes calcification being exacerbated by the advancement of the patient's CKD (Jennings et al. 2013).

In early 2010 having reached stage 4 CKD, the patient received an extensive colour duplex ultrasonography mapping of her peripheral vascular real estate to assist her nephrologist and vascular surgeon in determining the most appropriate options for her VA. Colour duplex ultrasonography is regularly used for this purpose being non-invasive as well as a reasonably accurate method for identifying complications such as functional focal stenotic lesions within the patient's fistula circuit (Chandra et al., 2010). Elderly people with diabetes leading to ESKD as is experienced by our 70 year old female patient, frequently suffer a higher prevalence of co-morbidity and disability. Moist et al. (2012) suggest that while the timing and progression of CKD are important factors, additional considerations regarding timing and creation of a patient's VA necessitates the inclusion of the biology of the patient's vascular beds in the patient's assessment.

During these final stages of the patient's CKD, it was determined through discussions between the patient, her family, nephrologist and VA surgeon to abandon any attempt of an arterio-venous (AV) fistula conduit for haemodialysis. Together with the patient and her family i.e. husband, daughter and three sisters educated consensus, it was decided to insert an abdominal catheter for peritoneal dialysis by

utilising the patient's peritoneal cavity to work as a semipermeable membrane for dialysis. This option of RRT was unsuccessful which was attributed primarily to the patient having developed a large abdominal hernia. This course of RRT was abandoned and the abdominal peritoneal catheter was removed and the hernia repaired.

In August 2010, a tunnelled and cuffed catheter was inserted into the patient's right internal jugular vein in order to reduce the risk of short and long term complications (Polkinghorne et al., 2013), such as tunnel infection and dislodgement. Both patient and family took responsibility for assessing for signs and symptoms of infection, the jugular vein catheter dressings remained intact and lumens remained capped and clamped as per current guidelines. This was dedicated as the patient's VA for haemodialysis central venous catheter (DCVC). In August 2010 the patient also commenced on a chronic haemodialysis schedule culminating 4.5 hours thrice weekly. It was planned that the DCVC would only serve as a bridging VA option while an AV fistula conduit was surgically created in the patient's non-dominant left forearm. Establishing a mature AV fistula conduit, maintaining the patient's VA to keep it viable and reducing the risks of VA complications, is directly aligned to patient morbidity and mortality and therefore costs to the patient, their family, the community and healthcare services (Sgroi et al., 2013).

Three common surgical options for a patient's haemodialysis VA include AV fistula conduits of autonomous arterio-venous fistula (AVF), synthetic fistula predominantly composed of plastic polymers as an arterio-venous graft (AVG) or alternatively a DCVC (Jennings et al., 2011). This case report includes all three.



AVFs continue to be recognised as the first choice for patients requiring repeated access for haemodialysis therapy owing to their long term patency, lower incidence rate of functional stenotic lesion affecting the flow of the blood through the fistula conduit, thrombosis and infection (Feddersen & Roger, 2012). Clinical practice guidelines (CPGs) across Australasia, the USA and Europe promote AVFs (primarily radio-cephalic) pose the least risk to a patient's mortality by maintaining superior patency and lower complication rates as opposed to AVGs or DCVC (Lopez-Vargas et al., 2011).

Around 75% of Australian and New Zealand patients were receiving haemodialysis through AVFs for their ESKD (ANZDATA, 2013). However, the proportion of patients commencing haemodialysis using a DCVC reportedly is as high as around 60% of Australian and 75% New Zealand patients (Polkinghorne et al., 2013), similarly this is generally reflected across Australasia, Europe and the USA (Lopez-Vargas et al., 2011). In the USA, for example, although 31-34% of patients may have maturing or functioning AVFs, around 80% of patients commence haemodialysis therapy using a DCVC as their VA (Polkinghorne et al., 2013). This has significant implications to patient outcomes and healthcare. Moist (2014) reports patients are 2-3 times more likely to be hospitalized using a DCVC as their VA owing to infection, spend 1.7—3.7 times longer in hospital and die from septicemia compared with patients who are using AVFs. DCVCs carry the highest risk of complications including infection, thrombosis and reduced efficiency of removal of toxins and wastes from the body (Polkinghorne et al., 2013 Feddersen & Roger, 2012, Bessias et al., 2008).

By April 2011, the patient was experiencing poor haemodialysis adequacy, inferred by inadequate clearance of toxins and wastes during her haemodialysis therapy using her DCVC as a VA. Although she had not experienced any other DCVC related complications, the patient and her family were resolute that their goal was to have an AVF created as her VA. The family with knowledge of the risks versus the benefits of continuing on a path of haemodialysis therapy through a DCVC agreed that an autonomous AVF still posed for her the most effective VA option to ensure the patient's long-term survival, enhancing QOL and wellbeing (Feddersen & Roger, 2012, Chandra et al., 2010). Unfortunately, the primary attempt to create the patient's AVF in her left forearm had been unsuccessful. The AVF had failed to mature owing to poor arterial inflow attributed to the patient's diseased distal radial artery and the AVF was abandoned. Atherosclerotic disease including calcification is commonly found to be pre-existing in the vessels of this group of patients, with the distal third of the radial artery most affected, resulting in many new AVFs, surgically created in patients distal forearms failing to mature (Swinnen 2011).

In September 2011 with the patient continuing to receive her haemodialysis therapy via her primary DCVC suffered further reductions in her dialysis adequacy, a result of the inability to achieve adequate haemodialysis blood flows of 300 ml/min or greater. This was attributed to the thrombotic partial occlusion of her DCVC. The DCVC was successfully cleared with the installation of urakinase within both DCVC lumens for 2 hours and then withdrawn prior haemodialysis therapy. Although DCVCs may be intended to remain in situ as a bridging device, they often remain in use as a

patient's VA for many months or even as a permanent VA remaining in place for years, as seen in this case.

In October 2011 a second attempt was made to create a proximal AVF in the patient's left upper arm utilising the brachial artery and cephalic vein as a brachio-cephalic AVF with the anastomosis in the patient's cubital fossa. Post construction, the AVF developed over eight weeks. However, barely a short usable segment of six centimetres of the AVF vessel was able to be cannulated as the remaining length of the vessel was too deep to safely access even with the use of a longer cannula. The short superficial segment of the AVF vessel was utilised using two appropriate sized 16g cannulas for the initial three haemodialysis therapies. During the patient's fourth haemodialysis, an attempt to cannulate the vessel resulted in the needle tip perforating the back wall of the vessel and blood infiltrated into the surrounding tissue. The AVF thrombosed a few days later owing to a functional stenotic lesion occluding the arterial inflow to the patient's AVF within the anastomosis. A second stenotic area was uncovered within the outflow segment of the vessel proximal to the patient's heart. Any amenable plan to regain the functionality of the patient's AVF through endovascular intervention was abandoned. With the patient's AVF being so new, thrombosis may have been exacerbated by episodes of hypotension and or hypovolaemia which frequently cause AVFs to fail (Fahrtash et al., 2011) particularly seen in cases of new, maturing AVFs and when the patient has already been receiving haemodialysis therapy via a DCVC.

The functionality of the patient's DCVC was an issue with poor dialysis adequacies and the patient and family were keen to try once again although they

were conscious of the risks of further surgery and possible failure of a third AVF. In April 2012 a third attempt of a brachio-cephalic AVF in the patient's right proximal or upper arm by surgically creating the anastomosis of her AVF in the right cubital fossa was undertaken. This time, the patient's AVF was left to mature for a total of four months. During this time the patient's AVF was not cannulated to allow maturation of the AVF vessel and decreasing the risk of complications. Regular monitoring and surveillance was initiated. The patient's AVF and DCVC remained the responsibility of everyone, involved in the patient's care (Feddersen & Roger, 2012). The family were vigilant monitoring the patient's AVF function by checking that the thrill and bruit were present over the AVF anastomosis site, along with the clinical nurses monitoring the patient's AVF. Monitoring also incorporated a nurse utilising grayscale ultrasonography weekly to assess both the maturation of the patient's AVF and early detection of associated complications. During this period, the patient's family informed the nephrologist that they had noted the patient's primary DCVC had become dislodged and therefore required rewiring with a replacement DCVC in the same site.

As this was the patient's third attempt to establish an AVF, the patient's AVF was initially unconventionally cannulated with one needle as a routine for a number of weeks. Therefore reducing the risk of trauma to the AVF vessel and arm, by returning her blood from the haemodialysis circuit through alternating the use of the patient's two DCVC lumens. The technique achieved additional benefit to the patient by improving her dialysis adequacies. During a physical assessment one month later, along with utilisation of a grayscale ultrasonography, a clinical nurse observed a

stenotic lesion had developed eight centimetres above the patient's AVF anastomosis. The vascular surgeon confirmed the presence of a functional stenotic lesion being 8-10 centimetres above the anastomosis of the AVF during a non-invasive colour duplex ultrasonography. The stenotic lesion was treated using angioplasty, a fixed stent and finally a drug eluting stent. Drug eluting stents implanted during percutaneous transluminal angioplasty aim to reduce the risk of functional stenotic lesions re-occurring (de Leur et al., 2013).

In November 2012 the patient's AVF thrombosed followed by a three day delay to revive the patient's AVF complicated by a lack of available theatre time. The patient was eventually moved onto another healthcare area to gain access to an operating theatre. It was determined that the underlying cause of the patient's thrombosed AVF was an anastomotic stenosis. In the course of endovascular intervention, the brachial artery was perforated and the AVF was lost in favour of saving the patient.

In March 2013 the patient and family agreed to revisit the patient's right arm for a VA, this time using the brachial artery and basilic vein for an AVF. Being the fourth attempt at creating a viable AVF, initially the patient's brachio-basilic AVF developed slowly and cannulation was not attempted. The vessel was deep and required further surgical intervention to transpose the basilic vein. After three months of regular monitoring and surveillance, a functional stenotic lesion was detected by a clinical nurse on physical examination and grayscale ultrasonography approximately 4-6 centimetres above the anastomosis. This was confirmed by the vascular surgeon utilising colour duplex ultrasonography. Unfortunately, the AVF thrombosed before an

angioplasty was performed and any attempt to revive the AVF has been abandoned for any time in the near future. The patient continued to dialyse through her DCVC obtaining adequate though not optimal haemodialysis clearances of her body's toxins and waste products.

In October 2013 it was time to change strategy and place an AVG in the patient's right thigh. Previously avoidance of placing an AVG in the patient's thighs was attributed to her experiencing severe peripheral neuropathy in her lower limbs and the patient's healthcare comparing the aetiology of fistula conduits. Synthetic AVG conduits are more prone to infection and unpredictable failure from neointimal hyperplasia compared to that of AVFs (Feddersen & Roger 2012). A combination of using a synthetic graft along with the patient's already diseased vessels including pathological irregularities such as arterial medial fibrosis and calcification reduced the likelihood of the patient's synthetic AVG survival (Allon et al., 2013). The patient's right thigh AVG was not cannulated for eight weeks after surgery and then only using the venous return limb of the AVG loop as the patient's surgical wound over the arterial limb of her loop was slow to heal. The patient's haemodialysis therapy was continued for another six weeks by cannulating with one needle into the inner venous limb of the AVG loop for removal of blood and returning the patient's blood via her DCVC.

The patient's leg wound healed and at four months after her surgery, two cannulas were used one in either side of the AVG loop with the second cannula returning the patient's blood from the haemodialysis circuit. The patient had commenced warfarin prophylactically at the time of surgical placement of her AVG

and was experiencing regular episodes of prolonged bleeding from cannulation sites after removal of her cannulas at the end of haemodialysis therapy sessions. The patient had similarly experienced constant bruising secondary to cannulation of the AVG in her right thigh. The warfarin was ceased after one final incidence when the patient required transferring to the hospital's emergency department post haemodialysis, having continued to bleed from a cannula site for 6 hours. Follow up surveillance coloured duplex ultrasonography had revealed a thrombus that continues to be monitored within the venous anastomosis or outflow of the patient's AVG circuit. The patient's therapeutic warfarin regimen was replaced with daily clexane injections (enoxaparin sodium), fish oil capsules (omega-3 polyunsaturated fatty acids) and aspirin tablets (acetylsalicylic acid). No further episodes of prolonged bleeding or excessive bruising have reoccurred.

By October 2014 the patient's haemodialysis adequacies improved and the patient correspondingly reporting enhanced QOL and wellbeing. The patient's DCVC remains in situ with no immediate plans for its removal and continues to be used as a VA routinely for at least one of the patient's haemodialysis therapies second weekly. The practice of the patient having a DCVC as a secondary VA option continues to enable resting her AVG and limb if cannulations are unsuccessful, should the AVG sustain trauma, requires intervention or fails.

## **Discussion**

Changing demographics have resulted in greater numbers of elderly populations who reach ESKD having co-morbidities. Increased complexity in patients requires extensive patient assessment to determine the most appropriate VA for their

individual circumstance (Al-Jaishi et al., 2013) while balancing the risks versus the benefits to the patient. Although an autonomous arterio-venous fistula (AVF) is regarded as the first choice for a patient's VA (Feddersen & Roger, 2012) this case demonstrates that effective assessment may lead to alternative VA routines being adopted including a mix of AVF & DCVC, AVG & DCVC. A patient's AVF should be surgically placed well in advance of the patient commencing haemodialysis therapy and will depend on patient-related factors and their local facilities (Polkinghorne et al., 2013). UK guidelines recommend the surgical placement of a patient's AVF by 3 months but no earlier than 12 months prior to the patient's anticipated start of haemodialysis therapy allowing time for any necessary revisions of the patient's AVF (Fluck & Kumwenda, 2011). Australian and New Zealand clinical practice guidelines (CPG) advocate that when a patient is reaching the late stages of CKD 3b/4, it is crucial to have a planned pre-dialysis pathway including patient and family/carer education, vascular assessment, creation of a vascular access and subsequent maturation time (Polkinghorne et al., 2013). Late referral restricts the opportunity for patients and family/carer education and may limit meaningful involvement in decision-making regarding treatment options influencing patient satisfaction, adherence to treatment and QOL of both patient and family/carer (Goovaerts et al., 2015).

## **Conclusion**

There have been mixed reports on the viability of AVFs for elderly patients compared with AVGs and DCVCs. Current evidence remains unclear as to what is the best option of VA for an elderly patient to provide optimal haemodialysis therapy and patient outcomes. Issues that are key elements in decisions regarding the most



advantageous options of VA for an individual include the patient's life expectancy, QOL goals and wellbeing. Equally important in the multi-disciplinary healthcare are the patient and their family and/or carers. The responsibility of a patient's VA is the responsibility of all those involved in and with an interest in the patient's care. Healthcare education for patient and family/carers, which supports their decision-making processes, may be compromised when time is not available and foreseeable procedures are not adequately planned.

### **Postscript**

In January 2015, sadly this patient passed away. Incidentally, her AVG was still functioning before she passed. While reflecting back, I question what can other people learn from this patient's journey? Around four years ago I had asked this patient what did she really need and her answer was 'I want to live, not just to stay alive but to live, to be there for and with my family, particularly for my two grandchildren'. Therefore, the patient's goal was set to fulfil her expectations. My reply back then was 'okay, let's work together as a team to do just that'.

Today the patient's sister visited the haemodialysis unit, where the patient had received her haemodialysis therapy and care. She said she was 'so grateful for the care her sister had received' and spoke about the many ways that the patient and her family were welcomed and how their opinions and needs were respected and embedded into the patient's care. Through allowing patients and their family to have a voice, to set their goals, and incorporating the patient and their family as team members in healthcare we effectively implement family nursing. By being with the family we can learn about what is important to them as a family, the importance of

providing support for them to live their goals, obtain QOL and wellbeing, rather than the caring for the patient with a system aim of merely remaining alive.

## **The continuing story**

As society's attitude toward patients' self-efficacy in healthcare continues to evolve there has also become limitless access to educational material relevant to patients who are living with CKD-ESKD and RRTs options such as haemodialysis requiring a viable vascular access (Porter et al. 2013). In my experience however, from working with teams of multi-disciplinary healthcare professionals, patients and their families and friends as carers, there can be mixed perceptions toward what level patient and family/carer involvement is acceptable. This observation is not directed at any particular group involved in the patient's care, or those parties who have an interest in the patient's care including the patient themselves. Differing perceptions of self-efficacy can create tensions in the nurse-patient-family relationship. Such tensions can be particularly evident when patients and family/carers report they feel rushed and or have unsatisfactory healthcare education to translate into knowledge that will enable them to make important life changing decisions. This is a crucial element in the patients' and family's/carers' healthcare experience, particularly when healthcare professionals do not take into consideration the patient's and their family's/carers' individual needs for their health literacy (Campbell & Duddle 2010), which can vary at any point in time.

A significant number of elderly patients pass away in the first three months of haemodialysis or peritoneal dialysis therapy and therefore these RRTs can impair the patient's QOL as well as their death (Couchoud et al. 2015). Hence, patients require an early prognosis and personalised care planning that is based on the patient's and

their family's/carers' choices. Problems can occur however, when patients' and family's/carers' personal goals for their QOL are not prioritised, which may become particularly disconcerting when these goals are not aligned with a patient's prescribed treatment regimens. Historically medical models concentrated on patients' adherence to prescribed treatment regimens however there has been an empowering shift, of expectations for patients who are living with CKD-ESKD, to self-management models of care (Washington 2013). This new model of care incorporates and respects patients' values, preferences and beliefs, encouraging patients and family/carers to participate in care.

The following Chapter three, presents the outcomes of a narrative review of the literature conducted at the beginning of this research project titled 'Care of a patient's vascular assess for haemodialysis: A narrative literature review.' This literature review utilises the bioecological model to guide the thematic analysis of current literature.

## CHAPTER THREE: A NARRATIVE LITERATURE REVIEW

### Introduction

The aim of this narrative literature review was to explore the current understanding of what factors influence the care of VA for haemodialysis. As utilising a narrative literature review allowed the synthesis of the known literature pertinent to the research question into a succinct model or unique order to enable new understandings to emerge. The bioecological model was used to guide the thematic analysis of the literature which revealed five themes related to care of a patient's VA: patient experience; relationships-empowerment and shared decision making; environment of healthcare; time; and quality of life as the outcome of care.

The narrative literature review for this CS has been synthesized into a journal article, which has been published online in September 2015 through the Journal of Renal Care, and will be available in the hard copy first issue 2016. The online version of this article is embedded in this dissertation as Chapter Three, preserves the published format. The article is available as the following reference:

Cowan D., Smith L., Chow J. (2016). Care of a patient's vascular access for haemodialysis: A narrative literature review. *Journal of Renal Care*, vol. 42, no.2, pp.93-100, via Wiley Online Library. First published online 30 September 2015. (see Appendix 4. 'Publications and presentations during candidature.')

# Care of a patient's vascular assess for haemodialysis: A narrative literature review

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## Summary

**Background:** Patients requiring haemodialysis have diverse clinical needs impacting on the longevity of their vascular access and their quality of life. A clinical practice scenario is presented that raises the potential of unsafe cannulation of a patient's vascular access as a result of minimal patient empowerment. Vascular access care is the responsibility of everyone, including the patient and carer.

**Aim:** The aim of this narrative literature review (1997–2014) is to explore the current understanding of what factors influence the care of vascular access for haemodialysis.

**Method:** A narrative literature review allows the synthesis of the known literature pertinent to the research question into a succinct model or unique order to enable new understandings to emerge. The bioecological model was used to guide the thematic analysis of the literature.

**Results:** The narrative literature review revealed five themes related to care of vascular access: patient experience; relationships-empowerment and shared decision making; environment of healthcare; time; and quality of life as the outcome of care.

**Conclusion:** The management of vascular access is complicated. Current available literature predominantly concentrates on bio-medical aspects of vascular access care. Contextualised vascular access care in the complex ecology of the patient and carers lives has the potential to enhance nursing practice and patient outcomes.

**Key Words.**

Empowerment, Haemodialysis, Kidney Disease, Vascular Access, Bioecology

**Biodata.**



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Debi's research interests are in the empowerment of patients and carers, through the holistic care of patients and their vascular access for haemodialysis.

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## **Background**

More than 9200 patients with end stage kidney disease (ESKD) received haemodialysis therapy in Australia in 2012, a 3% increase from 2011, with 61% of patients dialysing in satellite haemodialysis units (SHDUs). In 2012, 51% of patients were 65 years and older, with 27% of patients 75 years and older (ANZDATA 2013). The prevalence of chronic diseases including ESKD, are expected to continue to rise due to extended life expectancy, resulting in frailer elderly populations (Abdelhafiz et al. 2013).

Patients with chronic kidney disease (CKD) or in reaching ESKD have diverse clinical needs impacting on their own and their carer's goals for quality of life (QOL) (Kastrouni et al. 2010). Godbold (2013) defined carers as the patient's relative or friend whose role includes supporting the patient at home and or accompany them to haemodialysis therapy sessions, clinics and hospital.



Vascular access (VA) complications have been attributed to inadequate assessment, inappropriate cannulation practices and complications remaining undetected (Dinwiddie et al. 2013). Regular monitoring by skilled nephrologists and nurses utilising physical examinations is the cornerstone of VA surveillance programs however, VA surveillance is the responsibility of everyone involved in the patient's VA care, which can include the patient and carer (Feddersen & Roger2012).

### **Clinical scenario**

'Don't go there' said the patient indicating not to cannulate near the anastomosis of his autogenous arterio-venous fistula (AVF). I noted a recent cannulation site only a centimetre from his AVF anastomosis and not the recommended three centimetres. I inquired what had happened. He replied, 'I knew the needle was too close to my fistula, but I didn't want to say'. I asked him why. 'My fistula has been re-joined higher up my arm. Maybe the nurse didn't know, but I didn't want to upset her telling her where to go'. I gently pointed out that as his AVF was his life-line for dialysis it was important to discuss cannulation and the management of his vascular access (VA) with any nurse looking after him.

This clinical scenario became the impetus to undertake a narrative review of the literature exploring the current understanding of what factors influence the care of a patient's VA for haemodialysis? This paper presents the outcomes of a thematic analysis of the literature related to this question.

## **Aim**

The aim of this narrative literature review (1997 to March 2014) is to explore the factors that influence the care of a patient's VA for haemodialysis.

## **Method**

### ***Narrative literature review***

This narrative review has drawn on existing qualitative systematic and narrative review approaches employing a rigorous method (Green et al. 2006) and undertaken as part of a larger case study research project. In case study research, 'the articulation of what is already known about the phenomenon is called a descriptive theory' (Tobin 2010). In a descriptive theory, the aim is to synthesise the known literature pertinent to the research question into a succinct model or unique order, to enable new understandings to emerge. The descriptive theory is often completed during the early stages of a case study. This narrative review is on a mature topic, that is, where a large body of literature on the topic is available (Torraco 2005). Literature reviews completed on mature topics that explore a broad research question, are at risk of locating an excessive number of articles that fulfill the inclusion criteria. Excluding articles based on narrow inclusion and strict exclusion criteria is an appropriate strategy to help manage the review when it is appropriate to focus the research question or is congruent with the research methodology adopted, for example from within a positivist perspective. Such reviews favor randomised clinical trials at the expense of qualitative studies, so often the findings do not capture the depth and breadth of nursing or clinical research (Whittemore & Knafl 2005).

This narrative review has adopted an inclusive approach to the literature, which resulted in a large number of articles being located and initially reviewed. Similarly, Parry et al. (2014) used an inclusive approach and identified 2,887 records from which they included 19 publications in their thematic analysis. Our approach to managing the large number of records was to screen the record for quality based on type of research and publication. Once the quality was confirmed, each article was reviewed (see Screening below). Saxena and Adamsons (2013), whose seminal work has guided this narrative review, clearly demonstrated how to reframe literature using a theoretical perspective to underpin the decision process and research methods. Likewise, we utilised a thematic analysis underpinned by the Bioecological Theory of Human Development (Bronfenbrenner 2001), to guide the identification of articles to be included in the final report.

### **Theoretical underpinning**

Rather than presenting the narrative review in a chronological order with descriptive level of analysis reported through tables, the authors' goal was to inductively analyse the known and re-conceptualise the diverse knowledge base of the topic using an atheoretical lens not previously applied to VA care. The Bioecological Theory of Human Development guided the literature search and the thematic analysis of the literature (the data) by providing the key factors to explore. The key factors in the bioecological model are person, process, context and time (Lerner 2005). These four key factors aided the identification of the five themes discovered in the literature.

## **Search strategy**

The search strategy focused on key words associated with the established aim, aligned against the four key factors arising from the bioecological model as shown in Table 3.1. 'Key factors (within the bioecological model) and search terms'

	Search terms
Person	Patient experience, control, quality of life (QOL), wellbeing
Process	Shared-care, partners in care, active partnership, self-care, management, empowerment, decision-making, negotiating
Context	Haemodialysis, vascular access, arterio-venous fistula/graft, patient safety, quality improvement
Time	Schedule, stages, program, plan, organised

*Table 3.1: Key factors (within the bioecological model) and search terms*

Initially the search utilised key words associated with haemodialysis and vascular access of arterio-venous fistula/graft. Following initial screening of the results, a lack of the client's voice (patients, their family and friends as carers) was apparent. A subsequent search extended the criterion by including key words of patient experience and empowerment.

In an attempt to review a wide range of relevant literature a comprehensive search of databases and websites was undertaken. This included ANZDATA, KHA-CARI, Renal Society of Australasia, KDIGO, NKF KDOQI, DOPPS, USRDS, Renal Association (UK), The Cochrane Collaboration, ERA-ERBP, NICE, BMC, CINAHL, Clinicaltrials.gov, Flinders Academic Commons, Informit, JBI, Minnis Journals, Oxford Journals, ProQuest, Sage Journals, Science Direct, Wiley Publishing, Wiley Online and Wiley-Blackwell.

## **Screening**

The first author reviewed each identified paper systematically. The second author provided guidance on how to conduct a narrative literature review, how to determine inclusion and exclusion criteria and manage the analysis. For each paper, an evaluation of the reported methodology and level of evidence was undertaken. Papers that were not based on a specified research method or a synthesis of published literature were excluded. For this narrative literature review, the inclusion of diverse research methodologies (both experimental and nonexperimental research) was allowed. A total of 223 articles and texts were identified for initial inclusion. There were also two standards of VA management protocols identified through the literature search—evidence based clinical practice guidelines (CPGs) and clinical practice recommendations (CPRs) based on expert opinion (Mendelssohn & Benaroya 2008).

Through analysis of the 223 articles and texts identified for initial inclusion, 35 articles including three VA management guidelines were retained for inclusion in the narrative review. Each article was reviewed and key data were extracted. The results of this descriptive analysis are available in the online supplementary material associated with this article (see Appendix 5. 'Comparison and critical review of the literature included in the narrative review').

## **Data analysis**

Thematic analysis was employed as a way to create links within the literature, to gain a better understanding of the question (Braun & Clarke 2006). Hansen (2006) believes thematic analysis can help identify recurring patterns of interest. The Bioecological Theory of Human Development theoretically guided the thematic

analysis by providing the key factors to explore in the literature. The four key factors in the bioecological model—person, process, context and time—aided the identification of the five themes discovered in the literature: patient experience, relationships-empowerment and shared decision making environment of healthcare, time and QOL as the outcome of care.

## **Results**

### ***Theme one: Patient experience***

Patients living with ESKD have to contend with many changes to their bodies as well as their lives. Patients can be challenged by their dependence on haemodialysis (HD) therapy and their healthcare professionals to survive (Godbold 2013) and are required to be vigilant to protect and monitor their VA, as it is their life-line. Patients can experience differing cannulation techniques and care of their AVF or graft (Chow et al. 2011). This can result in the patient experiencing pain, anxiety and increase risks of serious complications, which can bring negative effects on the patient's QOL (Kring 2008). Patients, in addition to managing the demands of living with ESKD and the constant regimen of HD therapy, may find they are stigmatised for their chronic illness within their community. Patients can experience loss of employment, social and family support. A patient's perceptions about their life with ESKD and requiring HD therapy can be embedded with vulnerability and body awareness relating to their age and culture, resulting in stigma, mistrust and dependency (Richard & Engebretson 2010). Many older patients with CKD experience co-morbidities including diabetes, cardio and peripheral vascular disease. These co-morbidities can lead to difficulties in locating satisfactory VA site and cannulation options, which in

turn can affect VA outcomes (Moist et al. 2012). A patient's experiences can leave them feeling without hope, withdrawn and isolated. Patients can be at risk of becoming dehumanised by their clinicians. For example, clinical nurses refer to both the patient and the dialysis machine as one entity (Bennett, P. 2011). Instead, clinicians need to take into account patient and carer priorities and wishes, rather than providing patient management through a disease-oriented approach to patient care. Empathy with the chronicity of CKD and understanding of the effect that ESKD has on the patient's life, can help healthcare professionals to provide individualised and holistic patient care (Abdelhafiz et al. 2013).

***Theme two: Relationships-empowerment and shared decision making***

Patients treated in SHDUs can experience many challenges to their self-determination. Healthcare professionals caring for patients with ESKD need to acknowledge the rights of patients, which includes the question of who owns the body and who has the right to make decisions (Tims et al. 2007). Healthcare professionals can support patients and carers by incorporating seven key elements of empowerment into their clinical care to assist patients living with ESKD to gain a sense of control: self-determination; partnership; effective communication; goal setting; a caring environment; socio-political awareness and construction of knowledge (Tims et al. 2007). Effective relationships in healthcare are based on professionals, patients and carers working as partners in care (Barnes et al. 2013). It is through incorporating such practices and developing effective relationships that nurses and healthcare professionals can help achieve shared decision-making in vascular access care. Aasen et al.'s (2012) study of patient participation identified



three nursing practices common in the dialysis unit: firstly the most common approach is a paternalistic approach to nursing care, secondly, a less common approach based on patient participation and power sharing, and thirdly situations where nurses embrace autonomous decision-making. Consequently, healthcare professionals need to acknowledge both their own and the roles of the patient, family, carers, relatives and friends in negotiating and implementing healthcare. For example, in the United Kingdom (UK) patients and carers are often encouraged to be the experts of their care, rather than passive recipients of care (Chamney et al. 2012).

Education can be the key to empowering patients to attain an increased responsibility for their healthcare needs (Bennett, P. & Neill 2008). However, older patients with CKD and ESKD can have significant impairment to their cognitive capacity, associated with loss of kidney function. Therefore patient and carer healthcare education necessitates individualisation of content in response to personal needs and readiness to learn (Porter et al. 2013).

Self-management for people who have chronic health issues such as ESKD can be challenging as it involves juggling busy appointment schedules and navigating the healthcare system (Campbell & Duddle 2010). Even when patients and carers are empowered, sharing in decisions made about their healthcare can be overwhelming and in circumstances where patients and carers compare received care with care guidelines, unfulfilled expectations can create tension in the healthcare relationship (Godbold 2013). Achieving active roles can be dependent on the patient's or carer's abilities and personal circumstances at that point of time. Barriers can include travel and distances for treatments (Moist et al. 2008), plus costs and constraints on

alternative options. The patient or carer may believe it is not in their best interest to take on decision-making responsibilities (Godbold 2013).

### ***Theme three: Environment of healthcare***

Nephrology nurses working in a SHDU have the opportunity to preserve a compassionate culture within a unique clinical environment, possessing the power to provide complex high level care and support to patients as a high risk population (Kastrouni et al. 2010). Specialised clinical areas frequently develop cultures which reflect a unique environment. This culture includes advanced clinical practises, unit routines and traditions, formal and informal education, beliefs and knowledge base and a complex community of relationships with patients, carers and healthcare professionals (Bennett, P. 2011). Therefore, clinical nurses who work within a SHDU can develop a culture which is radically different from other nursing specialties and often unfamiliar to the patient and their carer.

Clinical nurses who work in SHDUs can influence peer and patient perceptions around a culture of power and oppression and what constitutes quality of patient care in the clinical environment (Bennett, P. 2011). SHDU nurses can also effectively advocate for the quality of patient care. For example, CPGs across Australasia, UK, Europe and the USA, generally rely on bio-medical assessments, for example Kt/V as mathematical measurements of blood results, to determine HD therapy outcomes (Naik et al. 2012). CPGs related to VA care should also incorporate the patient's perception of QOL (Ayoub et al. 2014) or well-being to help guide clinical practice and decision-making. Nurses, patients and carers who collaborate to implement empowered decision-making in a patient's healthcare can expand what constitutes

quality care outcomes and so cherish patients as real people who are struggling to live real lives (Bennett, P. 2011).

Regular monitoring is the cornerstone of patient VA surveillance. Skilled nurses completing physical examination can screen patient's AVFs and AVGs for dysfunction and refer if needed for more conclusive investigations e.g. Doppler ultrasound or angiography (Feddersen & Roger 2012). Nurse practitioners can improve the standard of nephrology patient care and be cost-effective in supporting medical care for this high risk population (Brown & Harvie 2010). Nurses completing VA assessment and taking on roles as vascular access coordinators, complement patient's own management of their VA (Polkinghorne et al. 2009).

#### ***Theme four: Time***

Time is a major factor for patients, carers and clinicians influencing patient and carer experience and outcomes of VA care. Planning a patient's timely pre-dialysis pathway is time consuming and can be complicated. There can be barriers, especially when patients require an urgent start to haemodialysis (Lopez-Vargas et al. 2011). When patients reach ESKD without experiencing a timely transition of care, patients and carers can perceive a lack of control and left confused about living with CKD (Key 2008). Optimally early referral (one year prior to start of dialysis) can be initiated to allow time to prepare the patient for ESKD (Tordoir et al. 2007). Patients require psychological preparation and explanations of all options of renal replacement therapies. The planning stage for haemodialysis and VA pathways, include individualised education supporting patient and carer empowerment and decision-making (Cho et al. 2012).

Time could allow for interventions to delay loss of kidney function and to correct symptoms such as anaemia, hypertension and the metabolic effects of CKD (Abdelhafiz et al. 2013; Tordoir et al. 2007). Planning which allows time for VA surgical placement and maturation prior to commencing treatment, can influence the viability of VA and potentially improve patient outcomes (Lopez-Vargas et al. 2011). Current UK CPGs propose the surgical creation of an AVF no less than three but no more than twelve months prior to initial HD therapy (Fluck & Kumwenda 2011). The European ERA-EDTA Nephrology Dialysis Transplantation CPGs recommend an early referral to a nephrologist and vascular surgeon (Tordoir et al. 2007). Similarly the National Kidney Foundation (2006) advises construction of a VA six months prior to anticipated commencement of HD therapy.

The Australian KHA-CARI guidelines propose the patient's referral to a vascular surgeon (especially for those with comorbidities), well in advance of their anticipated need for HD therapy (Polkinghorne, K. et al. 2013). Cho et al. (2012) found that early referral to a nephrologist and commencement of patient education resulted in a reduction of 8.7% to unplanned urgent start of dialysis, shortened patient hospital stays by 42% and reduced incident of patient VA infection rates. Patients benefit from a satisfactory period of time to allow for physiological evaluation, identifying and preserving veins, surgical creation of VA, close follow up during maturation and any necessary interventional revisions to ensure a healthy VA and subsequent optimal HD therapy (Feddersen & Roger 2012).

Patients receiving HD therapy can struggle with the requirements of time-consuming care (Hagren et al. 2005). Patients experience a time consuming

progression of VA cannulation procedures, frequently stressful and sometimes hazardous miscannulation and 'holding off' puncture sites (Dinwiddie et al. 2013). Patients can experience lengthy travel times, to and from dialysis units (Moist et al. 2008). This may well give rise to patients skipping or reducing their treatment hours of HD which in turn decrease QOL and increase co-morbidity and mortality. There are quality initiatives that utilise intra-dialytic time: for example, introducing exercise programs that encourage patients to improve their physical and psycho-social health. Successful intra-dialytic exercise programs are individualised, integrating the patient's individual needs and co-morbidities (Mitrou et al. 2013).

Patient assessment generally takes time and includes surveillance of VA for appropriate cannulation sites, screening for dysfunctional AVFs and AVGs, complications leading to stenosis, thrombosis and infection. SHDU nurses often view negatively the time necessary for accurate assessment, as they are frequently compelled to rush nursing care. As a result nurses may not take the time to properly assess and monitor VA, and this in turn supports the practice of cannulating the VA following old puncture sites from previous HD therapies (Wilson et al. 2010).

***Theme five: Quality of life as the outcomes of care***

Health related QOL is the state of a person's well-being incorporating physical, mental, social health and global sense of the person's health (Naik et al. 2012). The complexity of ESKD and vigorous medical regimens can decrease the patient's and carer's QOL. The patient's and carer's lives can undergo multidimensional changes as ESKD care requires a total lifestyle change (Zalai et al. 2012). The 'QOL of

patients...is related to a complex interacting factors of dysfunction' (Kastrouni et al. 2010, p. 126).

The chronicity of ESKD, the measures that need to be taken to protect VA and the maintenance of rigorous HD therapy regimens, can effect significant changes on a patient's physical and social lifestyles and their ability to live independently. Patients can experience physical and or mental fatigue (Bonner et al. 2010), pain, loss of social, sexual and cognitive function, inability to continue employment, schooling or studies (Kastrouni et al. 2010). Patients can develop altered perceptions concerning their self-esteem, body image, stress, depression, anxiety, and sadness (Zalai et al. 2012). Consequently, patients may well see themselves as a victim of their disease (Clarkson & Robinson 2010) and are frequently forced to reconsider their personal goals for QOL and well-being (Theofilou 2011).

Patients may try to enhance their QOL by firmly asserting their goals and making decisions about their care, however they may often find they are not well supported to do so. This can result in patients having conflicting goals when compared with those espoused by their healthcare professionals. Furthermore, juggling medical recommendations, struggling to maintain autonomy and being able to identify supportive healthcare professionals, can influence a patient's adherence to healthcare regimens (Godbold 2013).

Kastrouni et al. (2010) suggest that although patients with ESKD who undergo HD therapy experience similar factors that can diminish their QOL, interpretation of what is QOL may differ between individuals, countries and cultural beliefs. Similarly, Key (2008) points out this difference in understanding can also depend on the

individual haemodialysis unit's culture. To enable patients and carers to experience a better QOL, healthcare professionals need to devote greater attention to both psychosocial care and standard of healthcare interventions (Lopez-Vargas et al. 2007). However, healthcare professionals who provide holistic care in a supportive and safe cultural environment can help patients and carers achieve higher self-reported QOL (Kastrouni et al. 2010). Patients who gain some degree of autonomy, independence and QOL, have reported achieving enhanced outcomes compared with patients who maintain strict adherence to their treatment regimens. This implies that patient-directed goal setting can be a powerful influence in attaining acceptable QOL (Curtin et al. 1997). It is important that the outcome of care, as perceived by the patient, influences the ongoing management of VA and subsequent outcomes of care over time.

### **Implications for practice**

This thematic analysis exploring the literature was undertaken through a theoretical framework of the bioecological theory of human development. From the bioecological perspective, the identified themes are interconnected and revolve around the relationships and the ecology of healthcare experienced by the patient and carer. Considering the importance of 'time' throughout the patient's journey from CKD and throughout ESKD, may enhance patient care and help provide a more empowering and supportive culture within the SHDU's clinical environment. Partnering in healthcare can strengthen relationships with the patient and their family/carers. Stronger relationships may empower the decision-making processes, health literacy and enhance patients and family/carers experiences of VA care.

Time is a valuable and scarce commodity for patients who already have a compromised life due to their ESKD, with competing co-morbidities and time consuming treatment regimens. Patients can find themselves in a struggle with healthcare professionals and the healthcare system for control of time. In this struggle, healthcare professionals may use the patient's time to their own advantage when performing care, by not being mindful of the time-consuming impact of healthcare procedures or processes. Importantly patients and carers QOL and wellbeing are influenced by time. Healthcare professionals should look to recognise the value of time for patients and carers, and adopt a work approach that uses time mindfully, considerately and to the advantage of the patient and their carer.

Developing partnerships in care may also improve VA assessment and practices to improve the longevity of VA and health outcomes. Clinicians need to understand the patient's and family/carer's experience of living with the chronicity of ESKD, their goal of self-management and the benefits of shared-care and patient decision-making. Healthcare professionals should consider the wide range of factors which affect patient and family/carers QOL.

## **Conclusion**

This extensive search of the available published literature demonstrated current VA management is predominantly centred on planning the patient's VA, cannulation techniques, vascular mapping, surgical construction and intervention or revival of a patient's failed VA. A bio-medical approach to the maintenance of the patient's VA concentrates on the physiological aspects of VA care. As a result the literature fails to adequately guide holistic and contextualised VA care in the complex ecology of the



patient's and family/carer's lives. Understanding the relationships, roles and environment of care (together known as the ecology) is fundamental to providing holistic and optimal care that is empowering and respectful.

The management of VA is complicated. It requires optimal techniques of cannulation and the understanding of bioecological factors influencing the patient's healthcare outcomes to maximise the longevity of the VA. Nurses working to develop strong relationships in partnership with the patient, their family and their carers can implement CPGs and CPRs through a bioecological lens that values patient and carer empowerment and involvement. Utilising a holistic team approach in negotiating shared-care of VA has the potential to enhance nursing practice and patient outcomes. Further nursing research is required to understand the bioecological factors of VA outcomes, and to identify how best to implement clinical guidelines that effectively incorporate patient and carer decision-making and QOL.

**Acknowledgement**

None.

**Conflict of interest**

None.

**Authors contributions**

All authors contributed equally to the design of this research.

DC: (as a Higher Degree candidate) completed the literature search, initial data analysis, and first draft of the manuscript.

LS: (as principal researcher) oversaw the contributions of DC, helped draft the manuscript, confirmed analysis and approved the final manuscript.

JC: (as co-supervisor) reviewed the draft manuscript, advised on findings and approved the final manuscript.

## **The relationship between the context of article and this study**

The results from the narrative literature review helps build the descriptive theory of this case study. Examining the available literature within the scope of the research protocol (see Appendix 3. 'Narrative literature review protocol'), as pertinent to the research question, resulted in a new understanding to emerge of the bioecological factors that influence the care of a patient's VA for haemodialysis. The characteristics of this narrative review research protocol expanded upon the acceptable methods as outlined in Table 3.2 through the use of protocol typically implemented for a systematic review, where possible. For example, the research protocol included a defined aim, clear inclusion and exclusion criteria and a theoretical lens to guide an exhaustive search strategy and data analysis process.

As a descriptive theory, the aim was to synthesize the known literature pertinent to the research question into a succinct model or unique order to enable new understandings to emerge. The results of the analysis of the narrative review, included articles and guidelines are available online (see supplementary material associated with the published article and Appendix 5 'Table S1 Comparison and critical review of the literature included in the narrative review'.

The result of this narrative literature review has demonstrated that current management and care of a patient's VA is medicalised. As revealed throughout the literature, patients experience their VA management-care as predominantly centred on planning, cannulation techniques, vascular mapping, surgical construction and intervention or revival should a patient's VA fail. This demonstrates a biomedical approach to patient VA care concentrating on the physiological aspects of the

maintenance to a patient's VA. The current literature fails to adequately guide holistic and contextualised VA care in the complex ecology of the patient's and family/carer's lives.

The management and care of a patient's VA is complicated requiring optimal techniques of maintenance, surveillance and cannulation, while understanding the factors influencing the patient's healthcare outcomes to maximise the viability-longevity of the patient's VA. Renal nurses may have opportunities to develop strong relationships in partnership with the patient, their family and their carers.

Understanding the factors of care of the patient's VA, has the potential to enhance nursing practice and patient outcomes.

This narrative literature review was initially conducted in the early stages of the candidature and was updated prior to publication, after the submission of this article subsequent literature identified, has been included in the discussion Chapter Seven.

<b>Systematic review</b>	<b>Narrative review</b>
Pre-defined objectives	May or may not have defined objectives
Clear inclusion/exclusion criteria	Inclusion/exclusion criteria likely to be emergent
An explicit, replicable, exhaustive search strategy (including searches for unpublished studies to address publication bias)	Study selection depends on author selection and subjectivity
Systematic coding and analysis of included studies	Databases searched as required/preferred/available
Quality appraisal	Studies not appraised for quality
Meta-analysis (where possible to combine findings from a large number of studies)	Narrative synthesis, may be based on a subset of studies in a field
Protocol (project plan) for the review is developed in advance and undergoes peer review	Methodology not usually reported; difficult to replicate review
Review decisions are undertaken by at least two reviewers who work independently and compare results	Studies may be screened but criteria are not reported
Peer and editorial review	Peer and editorial review

*Table 3.2: Characteristics of systematic reviews and narrative reviews compared*  
Source: Summarised from Gough, Oliver, & Thomas (2012); Higgins & Green (2011); and Torgerson (2003)

The review methodology is further outlined in Appendix 3 (see Appendix. 3 'Narrative literature review protocol'), which includes the PRISMA diagram adapted from a systematic review method to the narrative review method.

## **The continuing story**

The findings uncovered during this narrative literature review, had given me cause to reflect on the past and current achievements of goals by Australian and New Zealand nephrology healthcare professionals taking on responsibilities of providing patients and their family/carers the most up-to-date evidenced based care. As nephrology (renal) healthcare professions we have formulated evidence into appropriate CPGs and CPRs, although these do not concentrate on patients' and family's/carers' care experiences, they are however regularly advanced with access to new evidence. Organisations such as ANZDATA collate Australian and New Zealand patients' CKD-ESKD statistical information which is then made readily available for research projects, CPGs, CPRs and healthcare policy updates. There are also a number of associations both national and international, whose members provide support and education for healthcare professionals, patients and family/carers. Australian associations include Kidney Health Australia-Caring for Australians with Renal Impairment (KHA-CARI), Australian Kidney Foundation (AKF), Australian and New Zealand Society of Australia (ANZSA) and the multi-disciplinary Renal Society of Australasia (RSA) with its sub-branch Nephrology Educators Network (NEN).

I have been privileged to be part of a team of NEN haemodialysis VA expert nurses and doctors completing a two year project from 2012 to 2014, creating an internationally available (to healthcare professionals) educational product, as an online e-learning education module for advancing the care of patients' haemodialysis VAs. I have also had the opportunity on seven occasions during my MN candidature to present my research at a University of Tasmania higher degree symposium, RSA

conferences and workshops and nephrology vascular access workshops (see Appendix 4. 'Publications and presentations during my candidature'). It is my determination to reach the goal of breaking through the challenges, by having an evidence base that effectively embraces the patient's and family's/carers' personal care experience and their goals for QOL, through the incorporation of evidence from this research project into internationally available CPGs and CPRs and healthcare policies.

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# CHAPTER FOUR: CASE STUDY METHODOLOGY AND CASE STUDY METHOD

## Introduction

The role of the nurse is rapidly evolving. The nurse's professional identity is both influenced and shaped by the context in which they work (Casey & Houghton, 2010). The nurse's role is influenced by the increasing complexity and demands of their community's healthcare organisations, to satisfy the needs and expectations of the patients, their family and friends as carers in conjunction with frequent limitations to available resources within their community's healthcare organisations (Anthony & Jack, 2009; Beanlands et al. 2005). One way forward in this transformation of practice is evidenced based nursing (Bonner & Lloyd 2011; van der Veer et al. 2011).

Research is central to the transformation of healthcare, through developing a discipline of nurses whose practices and interventions provide the patient and family/carers, with evidence based practice (EBP) (Brophy 2008). The relevance of research to EBP and its adaption to practice in nursing is that research can provide critical analysis for nursing practice when undertaken as a two-way practice-based production of research (Green 2008). This is a conceptualisation of nursing practice to research to practice, which emphasises a participatory approach to knowledge translation. It aims to utilise research more proficiently, by effectively leading changes in nursing practice to provide nurses with EBP guidelines that can promote effective healthcare delivery best practices (Green 2008; McGloin 2008; Bowen & Martens 2005).

Nurse researchers, like other social science based disciplines, formulate appropriate research questions about the nursing issue in context to the case (Brophy 2008). The research method is chosen to be congruent with the research question. Aimed to equip the nurse researcher with the most appropriate vehicle in which to provide a rich exploration of issues in relation to the type of research questions, the degree of control the researcher has on behavioural events and the focus of events, contemporary or historical (Yin 2009; Gillham 2000; Keyzer 2000).

A Case Study (CS) methodology can offer the most appropriate strategy for an investigation that focuses on contemporary phenomenon within the real-life context by way of providing a more in-depth understanding from a holistic perspective of 'what lies behind the more subjective evidence' (Gillham 2000, p. 7). CS approaches can frequently lead the nurse researcher to multiple questions, or a question which can address 'a number of previously unexplored dimensions' (Jones & Lyons 2004, p. 72) in providing a clearer understanding of the case and as such, the nature and the extent of a problem.

Currently a number of high quality CSs can be found in nursing literature however reportedly, CSs remained an underutilised approach in nursing research (Anthony & Jack 2009; McGloin 2008; Bergen & While 2000 ).

### **Background of case study research in nursing**

CSs as Bennett, A. (2001) proposes, have been utilised in a number of diverse disciplines such as anthropology, history, economics, political science psychology and medical science. Hammersley (2007) identified that CSs have been developing as a research methodology in the social sciences since the early twentieth century,

and are now evolving and being adapted by a diversity of disciplines. Thomas (2006) points out that in the nursing research lexicon, CS's only gained in popularity thirty years ago however, CSs in research have lessened in popularity over more recent years. Never-the-less a CS can be effective in exploring phenomena within the context of health and social care, predominantly in addressing topics associated within the scope of nursing practice (Anthony & Jack 2009; Brophy 2008). CSs in the social sciences are utilised by historians, in education, experimental physiology and in nursing (Smith, N 1990). CSs however, can be plagued by misconceptions and debate about trustworthiness, validity and vigour which may be attributed to a number of causes (McGloin 2008).

Firstly, Anthony and Jack (2009) suggest a lingering confusion in the name, the utility and nature of a CS. In the education of nurses CSs are utilised as teaching cases with a purpose for establishing a framework for discussions and debate among student nurses (Yin 2009). CSs that are utilised as examples in education can be deliberately altered to demonstrate a certain point more effectively. Whereas in CS research this type of manipulation would be unacceptable as a nurse researcher's role is to strive to report all CS evidence fairly (Anthony & Jack 2009). This confusion is reflected in nursing and education, as to whether a CS is a teaching strategy or a research methodology (McGloin 2008). This signifies that in the context of health care, there resides some confusion about the definition and application of CSs (Yin 2009).

Secondly, there is a notable lack of attention to CSs in two areas. Both Keyzer (2000) and McGloin (2008) point out, there is a virtual absence of topics that refer to

CSs in nursing research texts demonstrating an obvious neglect of writers within research textbooks to include CS research, as exemplified in Craig and Smyth (2007) and Hoffmann et al. (2010). Correspondingly, many earlier textbooks in the social sciences did not regard CSs as a formal research methodology and had often utilised CSs as a minor exploratory stage, as a precursor to some other type of research (Gangeness & Yurkovich 2006; Yin 2009).

The CS methodologies values, strengths and weaknesses at least in nursing research, may remain poorly understood by nurses (Woodside 2010). Inauspiciously, these issues may continue to feed ignorance and contribute to a false belief that as a research methodology CSs are weak lacking in rigor, robustness and validity (Amerson 2011; McGloin 2008). In many disciplines including nursing, CSs have utility not only as a research methodology but as a teaching method providing an invaluable tool for professionals to learn from real world events through a 'direct or vicarious acquaintance with particulars' (Sandelowsk 1996, p. 526). CSs can be seen as 'a linchpin for practice and research' (Chaiklin 2000, p. 47).

### **Definition and scope of a case study**

It is important to define what the word "case" signifies. A case is

'a unit of human activity embedded in the real world, which can only be studied or understood in context, exists in the here and now and merges in with its context so that precise boundaries are difficult to draw' (Gillham 2000, p. 1).

The term "case study" refers to human data in the context of an individual, group of individuals or organisation and a CS is about a single person, a family, a community

or an institution (Thomas 2006). Noor (2008) proposes however, that CSs are not intended to study entire organisations rather their intention is to focus on a particular issue, feature or unit of analysis. Both Bennett, A. (2001) and Yin (2009) however, discuss methodological approaches of utilising CS research across industries and organisations. Yin (2009) defines case as a concrete entity, event, action or occurrence and stresses a case is not to be defined by an abstract topic such as a hypothesis, theory, argument or concept. This may be confusing or even problematic for some researchers, particularly qualitative researchers and therefore, a case may be better clarified as a unit of analysis or in essence 'the heart of the study' (Jones & Lyons 2004, p. 72).

CSs are utilised to explore human phenomena as descriptive theory is employed to review theoretical underpinnings of a CS within relevant literature to a particular case, as well as presenting the context of a case (Smith, L 2011b). In CS research, the researcher has little control over the individuals while investigating a contemporary phenomenon in a real-life context (Gillham, 2000; Sandelowski, 1996). Boundaries between the phenomenon and the context cannot be clearly defined (Yin 2009; McGloin 2008). Researchers utilise a CS methodology to accumulate data as multiple sources of evidence from within a defined case or cases, in a defined context, event or place over a defined period of time (Casey & Houghton 2010; Brophy 2008). The case is situated as present-orientated even when the study includes historical data, is conducted within context of an individual or group of individuals such as a hospital ward or community unit, as in this CS of a SHDU community. Most importantly though, the researcher understands that it is a person's

values and beliefs that is the fundamental element which defines and influences the person's behaviours and experiences (Thomas 2006).

Although the term CS may carry a different purpose and definition in the clinical setting of nursing practice to the field of nursing research, a CS as a research inquiry can be effective through the utilisation of techniques to source and employ mixed sources of data (Chaiklin 2000). As Chaiklin (2000) suggest, this can enable the researcher to creatively and simultaneously view the case as a whole and in its parts or move those parts about to provide different combinations for analysis. Thus, establishing that CSs can be considered as an all-encompassing method of enquiry (Brophy 2008; Schneider et al. 2008). Equally, CS research can fit well within the discipline of nursing to provide a congruent approach to examining particularities in the everyday real-life experiences of individuals. CSs can provide a useful tool for knowledge translation, which has the potential of providing patients with individualised and up to date health care, based on EBP guidelines which can be adapted by nurses to their practice circumstances (Green 2008; Bowen & Martens 2005; Sandelowski 1996).

This may be an opportune time to explain that CSs can be utilised in the preliminary stages of research investigations to generate a hypotheses, which in turn may be tested in a later stage as a precursor to even larger studies or to ascertain if a further or larger study is justifiable (Evans et al. 2011; Gruba & Zobel 2011; Gillham 2000). Importantly this does not relegate the utility of CSs in nursing research, as having the singular purpose of only to form hypotheses for 'hypothetico-deductive

models of explanation' (Flyvbjerg 2006, p. 220). It does however, demonstrate that CSs can be utilised for a variety activities.

CSs have an inherent flexibility which provides the nurse researcher with opportunities to utilise a CS methodology for a variety of projects. An example of CS research is its utilisation to determine a CS's site selection, for a multisite mixed method CS with an aim 'to capture the broader context of the research, as well as any contextual nuances that shape policy implementation' (Sharp et al. 2012, p. 34).

There can be advantages in employing a CS methodology, as it can retain sufficient flexibility for a person-centred investigation, invaluable when investigating human phenomena, which seldom follows a predictable course (Keyzer 2000). Research questions are frequently multifaceted in human science, addressing both social and behavioural phenomena of interest and are often extremely complex and therefore frequently intertwined (Tashakkori & Teddlie 2010). Which is why the adaptability of a CS methodology may be more appealing to nurse researches from across a wide range of clinical settings and specialities in urban, rural or remote communities (Keyzer 2000). Nurse investigators may be drawn to utilising a CS methodology to address the multidimensional nature of human phenomena in their every-day healthcare (Keyzer 2000).

The flexibility of a CS represents the fluidity and flexibility which can embrace change by accommodating changes to the paradigmatic boundaries in that the 'methods utilised in research are pragmatically rather than paradigmatically driven' (Casey & Houghton 2010, p. 45). Therefore, a CS methodology can provide nurses with the opportunity to utilise and harness a synergy that can lie in the application of a

mixed methods approach. CSs can provide nurses with useful methods or techniques for multiple sources of data collection to deliver a round picture of the phenomenon or series of events (Noor 2008). Thereby CSs can provide a stronger, convincing and accurate methodology of enquiry (Casey & Houghton 2010).

CS research merits the consideration of nurse researchers as it can provide a comprehensive and flexible approach to address the many challenges of a community's healthcare demands while dealing with limited resources (Anthony & Jack 2009). A CS's flexibility can tackle human-centred surprises and issues more effectively in regard to unforeseen events that may unfold throughout the data collection and analysis of the study (Yin 2009; Tashakkori & Teddlie 2010; Brophy 2008; Jones & Lyons 2004; ). It is a CS's flexibility and the utilisation of triangulation methods of data analysis that support CSs may better be defined as a research methodology (Keyzer 2000). Keyzer (2000) proposes, that similar to action research a CS approach can provide the nurse researcher with the opportunity not only to predetermine their research methodology, but through their own reflection throughout their investigation, the nurse researcher can initiate changes, make adjustments to their methods or choice of methods that they are utilising. Unlike action research or ethnographies which are aligned exclusively within qualitative methods and are more aligned with a post-positivist stand, CSs are not restricted to any specific paradigm of research (Keyzer 2000). Thus, greater levels of understanding could be achieved through utilising a research method of journaling my reflections upon the participants' responses of one's personal experiences and perceptions. As CSs are unrestricted by any particular paradigm of research this method allowed for boundless reflection



upon an individual participant's responses, to be extended across their group responses i.e. patient, carer (family and friends) or staff member. I was then able to extend my reflections to compare the group responses, which had provided a method of triangulating of data sources to support and validate the study's findings (Brophy 2008; Jones & Lyons 2004; Keyzler 2000). Therefore as reflection journaling is not necessarily restricted to any particular paradigm of research, this was a method of research whose utility extended across all information afforded within participant responses. This had correspondingly facilitated my own reflection upon each participant's responses to multiple choice answers to questions (quantitative) and their stories in response to the open ended questions (qualitative).

CSs can be utilised in nursing, to process clinical issues which have been identified and articulated into purposeful research questions which serve dual purposes. Firstly, the research question in clinical practices can serve to set down boundaries and although frequently not clearly defined, the CS's boundaries can serve to clarify the research methodologies particular focus and therefore the course of the research inquiry. Secondly, these boundaries can serve as a measure, the nurse researcher can utilise to adapt throughout the study, in an endeavour to keep the CS project from getting too large or unfocussed (Tashakkori & Teddlie 2010; Yin 2009).

### **Sources of data in a case study**

The CS's data can be amassed as a detailed but comparatively unstructured collection of information having been gathered from a number of sources including narratives from the individuals themselves (Bergen & While 2000). A CS's data can

concern the background, culture, environmental characteristics and interactions between the individuals and vary from an investigation of a simple single brief case to a very complex case examining larger numbers of variables within a case. CSs can be used to test a hypothesis or for the generation of theories (Thomas 2006). The scope of CSs can begin with studying an individual and as a continuum, may end with a community of individuals or even a larger entity such as studies directed across entire organisations (Chaiklin 2000).

A mixed method approach to a CS methodology can provide the nurse researcher with a more complex approach to study the more complex issues that social science researchers now face (Torrance 2012). CS approaches can provide the researcher with an opportunity to abstract and collate data from multiple sources of evidence as the main and prevailing focus of single case, defined as an intrinsic CS this has a potential of uncovering multiple realities from data derived from multiple sources about an individual or individuals (Smith, L 2011b). CS's data sources could include direct observation, interviews and surveys, as well as archival records, physical artefacts and from the researcher's own documentation (Gillham 2000). Utilisation of a mixed method approach in simultaneously taking into consideration multiple factors, which can be a CS's strength in optimising understanding and similarly to all scientific studies 'test hypothesis and establish cause' (Chaiklin 2000, p. 47).

A mixed method approach to a CS can offer considerable advantages such as cross-validation or complementing the case's individual findings (Bergman 2011). Utilising both observation and statistical analysis of the case can employ a mutuality

of approaches incorporating both qualitative and quantitative research methods (Amerson 2011; Anthony & Jack 2009; Jones & Lyons 2004; Keyzer 2000). Hence, nursing researchers utilising a CS methodology, by employing a strategy of applying multiple methods of data extraction and analysis are able to assemble these methods 'as a form of within-method and across-method triangulation' (Jones & Lyons 2004, p. 73).

Contrary to many research methodologies or methods that often dissect a part of the case for investigation, a CS methodology can provide the nurse researcher with the opportunity to review the case as a whole in its context which is of particular value to clinicians working in among the practice based disciplines (Brophy 2008; Sandelowski 1996). CS research can be structured to utilise a methodology of quantitative approaches combined with qualitative approaches or alternatively can be limited to a positivism approach of quantitative methods alone. More frequently in the social sciences however, CS research is reported as having utilised a post-positivism stand more in line with a qualitative approach. Qualitative methods have dominated CSs in the social sciences in both research and in clinical practices as reflected in the discipline of nursing, which has been credited to the strong narrative nature of CSs (Thomas 2006). Yin (2009) warns his audience that it is unwise for the researcher to associate CSs with any particular paradigmatic position, either from a positivist or post-positivist view, explaining that a CS project would be at risk of becoming more aligned to the researcher's paradigmatic position than to focus on the issues of the case (Yin 2009; Jones & Lyons 2004). Qualitative researchers may disagree with this proposal, as CSs have been strongly associated with qualitative methods. This has

been attributed to the emphasis of a CS's methodology being concerned with real-life phenomena and the post-positivism paradigm values closely aligned to qualitative methods descriptive qualities (Jones & Lyons 2004). Sandelowski (1996) supports Yin (2009) by further pointing out, that CSs should not be pigeon-holed into any one paradigm as the focus of a CS's methodology needs to remain firmly situated in the understanding of the "one" being the unit of human activity in a science of singular.

### **Credibility of a case study**

Bergen and While (2000) from a nurse researcher's perspective, argue that for CSs to be excepted as a robust and credible methodology of inquiry in nursing research, it is fundamental for the CS researcher to establish an appropriate subject matter, context and research aims. Radley and Chamberlain (2012) being strong advocates of CS's, suggest to replace the words "case study" with 'the study of the case' (p. 390). By which means, Radley and Chamberlain (2012) intend to provide a more progressive approach to achieving a better understanding of how people become cases and to provoke a rethink of theoretical assumptions, by which social life is currently understood both in research and in practice. Noor (2008) proposes that although a CS methodology is generally an underutilised research strategy for understanding complex real-life activities a CS is theoretically exciting and data rich. Noor (2008) suggests that by utilising a systematic approach to analysing a CS's strands of mixed sources of data, employing a method of triangulation within the study, can strengthen and confirm the study's findings.

## **Case study research applied in nursing practice**

CS's utilising a qualitative approach, are proposed to be in-depth intensive methods of inquiry into real-life by utilising multiple sources of evidence, concerned with understanding and explaining a social phenomenon, by focussing on the individual's opinions, attitudes and behaviours. Qualitative approaches are concerned with the effects of certain events on the individual such as cultural effects, their influences and the differences between groups of people (McGloin 2008; Gillham 2000). Therefore the relevance of CSs to EBP in nursing, is that CSs can provide critical analysis of nursing practice that can result in knowledge transformation leading to changes in practice, aiming to provide patients with evidence based (EB) care (Green 2008; McGloin 2008; Bowen & Martens 2005).

Tashakkori and Teddlie (2010) propose when the CS nurse researcher elects or acknowledges they are actually utilising a mixed method approach, they might well discover that a mixed method approach is a strategy which is more in line with the everyday human problem solving, in its utilisation of multiple approaches. CS methodologies can exhibit parallels with nurse researchers aligned with everyday human problem solvers. Through the nurse researcher finding evidence which they accumulate from a variety of sources to examine, make decisions and form impressions. There can be a plausibility of CS researchers building onto the day to day problem solving. Through employing a mixed method research approach to a CS methodology, nurse researchers can capitalize on the potential of optimising credibility and trustworthiness of a CS. This approach also emphasizes that through

their humanistic conceptualization, nurse researchers are of course human themselves (Tashakkori & Teddlie 2010).

At the initial stage of the inquiry, after identifying the issues or the problem in relation to the context of the case's environment, the nurse researcher will need to complete a systematic review of published peer reviewed literature. This task will serve to establish theoretical underpinnings of a CS while presenting the context of the case or cases (Smith, L 2011b) and possible empirical context of the investigation. This will demonstrate that the CS findings can add to a salient gap in the literature or incrementally to what is known previously about the identified issues (Creswell & Tashakkori 2008). A case is not discovered, it is there waiting to be investigated. The case requires the nurse researcher to formulate a good hypothesis or articulate a question or questions to form the focus of the CS (Evans et al. 2011; Tashakkori & Teddlie 2010; Yin 2009). The CS nurse researcher will select a methodology that is best suited to answer a particular question, questions or to furnish a particular hypothesis (Casey & Houghton 2010).

Yin (2009) refers to Platt (1992) as suggesting that CSs possess logic in their design and as a research methodology CSs are preferred when investigating human phenomena. Yin (2009) however warns the audience, that CSs should not be utilised as an ideological commitment, followed ceremoniously and in disregard of whatever the study circumstances may be. This can be exemplified by a researcher disregarding the case and its context of the inquiry, and instead choosing a methodology without placing their first priority by consideration of the environmental context and the issues of the case, which were raised warranting the need for the study.

The choice of the CS's methods are paradigmatically driven however, it is the role of the nurse researcher to ensure that the methods which have been selected, are then utilised according to their alignment with their paradigm, which serves to ensure the rigor of the CS (Casey & Houghton 2010; Yin 2009). CSs like many other methodologies can be complex and therefore laborious, often time consuming and can be costly. The complexity and demands of CS research projects are frequently underestimated, particularly by student and novice researchers (Evans et al. 2011; Keyzer 2000).

A CS methodological approach can provide the nurse researcher with an inherent flexibility and therefore can offer an opportunity not only to predetermine a methodology, but to have the ability to reflect on the progress of the investigation and then draw on the flexibility of the CS to make changes in their methods. This flexibility can be of particular advantage to student or novice researchers, in having an opportunity to initiate any necessary changes and carry out adjustments to the CSs methods such as, alternate or change the choice of methods throughout the investigation (Keyzer 2000). Research methodologies include processes or plans such as typographies. Typologies are in fact plans, destined to place order in the progression of the CS project to 'simplify complex phenomena for didactic, organisational, and communicative purposes' (Guest 2012, p. 141).

Nurse researches utilising a mixed method CS methodology as a social inquiry, would be viewed by many experts in the research community as following a methodology that is 'simply regarded as the proper way to do good research' (Torrance 2012, p. 11). The analysis of these mixed modes of data sources can draw

the nurse researcher to the very centre of the research activities, which can be further enhanced by the opportunity of combining diverse fields. Though the coming together of varying researchers' and analysts' experiences and paradigmatic positions, from a variety of disciplines of heterogeneous paradigmatic specialists utilising their various strands of knowledge skills (Tashakkori & Teddlie 2010).

As already suggested, in nursing as with many other social science disciplines, CSs have historically been effectively utilised as qualitative approaches, which can be attributed to a CS methodological approach of a holistic human-centred inquiry (Yin 2009; Jones & Lyons 2004). Qualitative CS methodologies continue to be utilised to study populations of all ages and in many contexts of nursing within institutional and community health care for education, research and knowledge development. Clearly suggesting CSs can add to nursing knowledge, both in cultural and trans-cultural contexts (Anthony & Jack 2009). CSs can provide nurses with a holistic form of inquiry, fitting well within the meta-paradigm of nursing while being appropriate for a vast variety of populations in the context of health care (Gangeness & Yurkovich 2006).

A mixed method approach to a CS can be utilised to conduct research which may replicate the findings or strategy of previous CSs and or through previous or multiple cases, expand the scope and generalizability of theories. For example, a CS can offer an alternative perspective or formulate a policy or clinical practice guideline. Exemplified by CS's providing a voice to marginalised or underrepresented people, highlight and suggest solutions for social injustices or inform nursing practice (Creswell & Tashakkori 2008).



Incorporating a qualitative approach to CSs can add validity to the case through construction of idiopathic generalisations which can serve collectively to make cross-case comparisons, constructed aggregations, allowing for synthesis and or interpretations of a CSs data (Sandelowski 1996). Aligned with a post-positivist paradigm by utilising qualitative, constructivist and interpretive strategies can provide a larger potential for nurse researchers to focus on social issues in healthcare (Mertens 2012). As a mixed method approach to CSs, qualitative methods can provide explanations to quantitative findings (Mertens & Hesse-Biber 2012; Jack 2006). Jones and Lyons (2004) propose by utilising a qualitative approach throughout a CS, there are petite-generalisations that lead to the refining of a generalisation which in turn form grand-generalisations. Therefore, developing more detailed theorisations including triangulation of multiple sources data (Jones and Lyons 2004). CS approaches can enhance the ecological validity and transferability of a CS. There is strength in participants experiences for example, reports of experiences relating patient's health and wellbeing can be 'far more valid than any statistical support for theoretical proposition' (Jones & Lyons 2004, p. 75).

Should the CS nurse researcher take a mixed method approach in their CS methodology, they can provide a deeper understanding based on convergence and dissonance in encompassing a mixed method framework (Bergman 2011). Nurse researchers utilising a mixed method approach for a CS, may more readily gather an appreciation, that with the successful application of a CS methodology to real-life phenomena, it may counteract any criticism of CS's right across social science disciplines (Sandelowski 2011; Flyvbjerg 2006).

It could be suggested that researchers are to some degree already engaged in utilising mixed method models in social science research to some extent without CS these nurse researchers even being aware. As Bergman (2011) proposes, often it is necessary, throughout a research inquiry (as is particularly noticeable within a CS methodology) when the nurse researcher reflects on the research questions, as seen within qualitative theoretical frameworks. Similarly this is also the case (if only weakly linked to quantitative methods) when the CS nurse researchers contemplate how or if a statistical technique of data sourcing or analysis needs to be included (Bergan 20110). Bergman (2011) recommends that 'a good mixed method research project includes an epistemology and ontology, a research question and a theoretical framework, sampling strategies, and interpretation that are conducive to both qualitative and quantitative methods' ( p. 273).

Although the CS nurse researcher may have initially justified an appropriate choice of methods of both data collection and analysis, it may be wise to be mindful of a less noticeable quality of research methods. That is, simultaneously as the knowledge about the research topic advances so may the research method or methods of data collection and analysis and therefore the nurse researcher may need to refine methods as CS progresses. Once again this demonstrates the adeptness of a CS, in the ability to draw on the flexibility of a CS methodology (Evans et al. 2011; Tashakkori & Teddlie 2010).

### **Processing the data: The analysis**

Case studies may be considered much more than a tool for data collection or a design feature alone, as having been historically utilised. A CS's methodology can be

a strategy to enhance knowledge about the case combining 'a logic of design, data collection techniques, and specific approaches to data analysis' (Yin 2009, p. 18). Although information produced from CS research cannot be generalised to populations it can however be generalised to theory. The CS project requires the development of a formal and presentable database. This can include the CS notes, predominantly the researcher's notes of interviews, recordings, observations and analysis of documents, tubular material from the research site or created by the researcher for example quantitative data and participant surveys, narratives as open ended questions and answers, CS documents collected and stored appropriately throughout the study. My utilisation of the method of reflective journaling as recorded in 'The story continues' sections of this dissertation at the end of each chapter, is evident of these processes. The CS's data base should be maintained in such a way that it can be auditable (Gillham 2000).

Data analysis can be dependent on the data collection methods utilised in the CS. In the case where qualitative methods have been utilised, the qualitative analyst endeavours to understand the "essence" of the case. The analysis evolves as a continual interchange between the data and the emerging finding, by focussing on how the case is uniquely formed. The qualitative analyst will closely scrutinize the particular case to find an idiographic explanation, learning all they can in an attempt to understand an individual's decision (Castro et al. 2010; Sandelowski 1996). For example, what may have happened that could have influenced a person's experience such as consequences, backgrounds and conditions in context person's cultural, biographical or temporal.

This methodology of analysis contrasts sharply from that of a quantitative variable-orientated approach to disaggregated variables as the analyst selects certain variables in an attempt to identify relationships between the variables (Sandelowski 1996). A mixed methods CS may include not only a mixed source of data, but also a mixed approach to data analysis. Research focussing on the relationships between variables, can be discriminative by targeting data that explains only the variations around similar observations, and so cannot consider the cases more closely as in the “whole” (Sandelowski 1996).

A CS methodology can enable the nurse researcher a detailed examination of the case, be it a single case or a unit, for CSs can be exploratory, observational and responsive (Yin 2009). The role of the CS nurse researcher, is to decide what elements comprise the case and even more significantly what way they connect or merge so uniquely together they inform the researcher, who can then discern what characterises the case (Sandelowski 1996). Sandelowski (1996) advises that although it may not have been initially intended, the researcher may indeed uncover from the case naturalistic or idiographic case-bound generalizations.

A CS's utilisation of a mixed method approach of both qualitative and quantitative methods can have the potential to enhance the ecological validity of a CS research inquiry and possibly carries far more strength than singularly relying on quantitative approaches as ‘any statistical support for a theoretical proposition’ (Jones & Lyons 2004, p. 75). Bergen and While (2000) advise against adopting a mixed method approach to CSs, if the researcher's intention is to discredit either qualitative or quantitative outcomes by setting out deliberately to uncover the methods

limitations. Instead a good CS research mixed method approach would be, to capitalise by dealing with these limitations to improve outcomes (Bergman 2011).

The knowledge gained through a CS, as a holistic investigation is integrated into the way in which the CS grows in its completeness, as the nurse researcher examines the elements of the CS. As such, it is how the conclusions provide the implications of the way the outcomes of the CS, becoming the wisdom through providing new insights, frameworks and theories. Through reporting the CS research, the nurse researcher forms the keystone, being the 'hypothesis-evidence-argument-theory (HEAT) structure of much research' (Evans et al. 2011, p. 149).

## **Case Study Method**

### **Research question**

What bioecological factors influence the outcome of nursing care of patients' vascular access for haemodialysis treatment?

### **Research design**

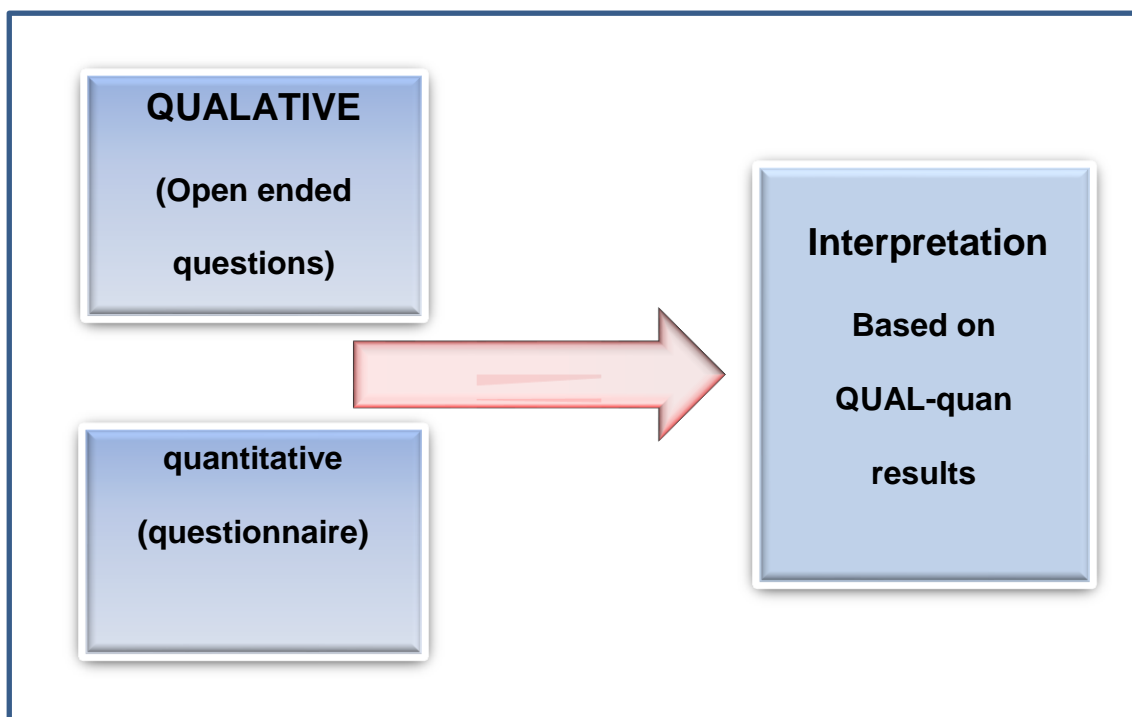
A CS design was selected as the most appropriate research design to answer the research question, although limitations impacting on the data collection arose. A mixed method case study allowed both qualitative and quantitative data to be collected through the questionnaires (see Diagram 4.1 'Mixed method research design'). People within this defined SHDU community experience the phenomena of living with and caring for the patient with a VA. As such their intimate experience with the bioecological factors that influence the outcome of care of patients' vascular access for haemodialysis treatment will be revealed. A CS methodology can provide

a rich exploration of personal lived experience in relation to the research question (Yin 2009). Part of the CS research design was the descriptive theory which has been completed prior to collection of new data. (The descriptive theory is presented in Chapter Two and Three and Appendix 2 ‘Understanding the journey travelled by patients and carers living with end stage kidney disease and haemodialysis’).

The parameters of this CS, was one SHDU community. Considering the emic perspective embedded in this CS it is important to note that as the researcher I was unknown to this SHDU community. Inclusion criteria for participants were of aged eighteen years and older and patients who had a VA for their haemodialysis therapy of either an AVF or AVG, which required cannulation in order to access the patient’s cardio-vascular system.

This CS utilised a mixed methods research design. A mixed method research design is defined as procedures for collecting, analysing and mixing both quantitative and qualitative methods in a single study or a series of studies to understanding a research problem (Creswell 2013). The CS mixed methods research design can be classified by Creswell and Plano Clarke (2007, p. 68) as an embedded correlational model. This research followed a Qualitative-quantitative (QUAL-quant) design with a major focus on qualitative data concurrently collected with a minor focus on quantitative data exploring correlations between variables (see Diagram 4.1 ‘Mixed methods research design’). The research design emphasized participant anonymity due to the nature of the study setting. Anonymity reduced the risk of identification within the study setting. Although participants’ interviews can be probed by the interviewer, anonymity cannot be maintained. Only confidentiality can be assured. For

further explanation of anonymity in this dissertation please refer to p. 88, p. 94, p. 99, p. 105, p. 107, p. 110, p. 214 and Appendix 6 ('Site specific information sheets').



*Diagram 4.1: Mixed methods research design*

## **Study Setting**

The research setting identified for this CS was one community based SHDU in South Western Sydney Local Health District. This SHDU community included patients who received haemodialysis therapy, their family members and friends as carers who accompany the patient to this SHDU community and the multidiscipline healthcare professionals within the SHDU.

The research setting identified had a total of fourteen chairs for patient's placements, providing haemodialysis for four shifts of patient's for their scheduled

thrice weekly treatment. The SHDU has been providing haemodialysis treatment for patients over the last four years and is part of renal care community comprising of two acute haemodialysis and a further three SHDUs within the health care area caring for 460 patients receiving regimens of haemodialysis therapy.

The population of in the SHDU setting includes:

- Patient numbers approximately 76
- Patient's family and carers
- Clinical nurses
- Allied health clinicians
- Nephrologists, vascular surgeons and interventionists

The study setting was a large SHDU community caring for approximately 76 patients. This SHDU community is situated within NSW in the region of the South Western Sydney Local health District (SWSLHD). At that point in time, 42 patients met the research inclusion criteria patient. Patients who required renal replacement therapy (RRT) for their ESKD receiving haemodialysis therapy via a VA of a native arterio-venous fistula (AVF) and or synthetic arterio-venous graft (AVG) requiring cannulation to access their cardio-vascular system for their haemodialysis therapy regimen met the inclusion criteria.

It was not appropriate or intended within the parameters of this CS to collect identifiable data. Therefore potentially identifying information such as patient age, gender, co-morbidities and medical history were not obtained. Similarly there was no information acquired concerning the relationship between patients and their family/carers. Likewise information regarding staff member demographics including



staff member positions in this single center CS was not obtained to maintain participant anonymity. Consequently participants' demographic information was limited so that participants remained non-identifiable.

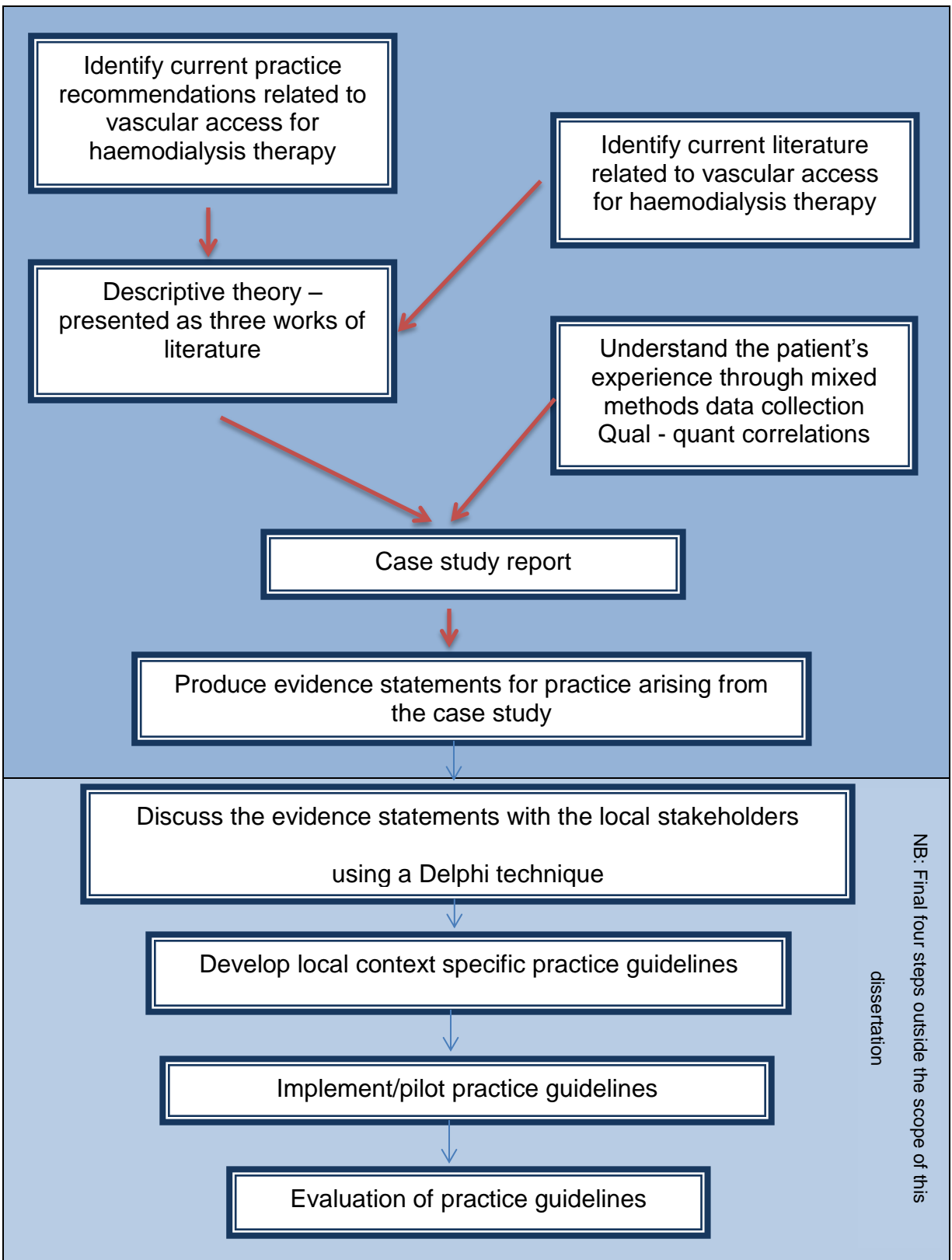
### **Purpose of this study**

The purpose of this mixed methods CS is to understand the bioecological factors that impact on the care and maintenance of VAs for people receiving haemodialysis. The triangulation convergence design (Creswell & Plano Clark 2007) will be used. The Bioecological Theory of Human Development (Bronfenbrenner, 2001) will theoretically underpin the convergence of the quantitative and qualitative data that explore the ecological factors influencing patient VA care outcomes. A self-administered questionnaire was made available for collection by all patients who met the research criteria, their family and friends as their carers (family/carers) and the staff members of this satellite haemodialysis unit (SHDU) community where the study was conducted. Qualitative stories were collected through the self-administered questionnaires that explore the experience of patients VA nursing care. The quantitative questionnaires are constructed from two standardised scales (SF-36v2® and the Family Satisfaction Scale) and two scales developed from theory (see Instrumentation p. 99). This study is unique in its use of life-narrative techniques to explore the patient's experience of VA care incorporating a family/carer and health professional perspective.

### **Diagram of research plan**

The research plan was based on the method proposed by Bosch et al. (2012) for the development of practice guidelines. Bosch et al. (2012) formulation is a practical and

stepped interactive process to develop recommendations for best practice has been adapted and extended for this CS, through including the step of understand the patient's experience (see Diagram 4.2 'Research plan' ). This research design extended the Bosch model by including primary evidence from patients, family/carers and staff members being the healthcare team. Defining best practice is one of the most crucial first steps in knowledge translation into recommendations. Importantly, best practice enhances patient outcomes when it is applicable to local clinical practice situations, assembled from the best available research-based evidence and is suitable for adaptation to the local ecology of healthcare. The research plan identified the appropriate completion point for a Master level project as 'Produce evidence statements for practice arising from the case study' (see Diagram 4.2 'Research plan'). The research plan also articulated the necessary steps to translate the findings from this research to practice. These are steps which are outside the scope of this study as represented in Diagram 4.2 'Research plan' represented as the final four steps.



#### *Diagram 4.2: Research plan*

### **Data distribution process**

The SHDU nurse unit manager (NUM) explained the purpose of the CS to patients, carers (family and friends) and staff members who were then offered their associated group, Site Specific Participation Information Sheet (see Appendix 6. 'Site Specific Participant Information Sheets'), their group specific questionnaire (see Appendices 7. 'Site Specific Full Survey for Patients', 8. 'Site Specific Open Questions for Family Members or Carers' and 9. 'Site Specific Open Questions for Healthcare Professionals') and an individual self-sealing envelope. As responses were to be placed by the participant into the provided envelope and sealed in order to retain participants' anonymity. The sealed unmarked envelopes were assembled by the SHDU-NUM and securely stored in the NUM's office until the period of two weeks had passed from the days of distribution and saturation of participation of patients, family/carers and staff members was achieved. All returned questionnaires were checked to ensure that they were within their envelopes and that they were both sealed and unmarked ensuring non-identification of participants by the NUM and myself.

The returned participant questionnaires contained both quantitative data and qualitative data entrenched within the participant's answers in both the multiple choice and open ended questions (see Appendices 7. 'Site Specific Full Survey for Patients', 8. 'Site Specific Open Questions for Family Members or Carers' and 9. 'Site Specific Open Questions for Healthcare Professionals'). De-identifying of participants'

was completed and participants' anonymity was ensured. Participants' questionnaires were then sorted into groups and as a result participants have been identified as follows. Patients for example P1, P2, P3 and so on, carers (family and friends) identified C1, C2, C3 and correspondingly staff healthcare professionals as S1, S2, S3 and so continued in this sequence. Participants' qualitative responses as data included within the open ended questions have been collated into word documents, one dedicated to each participant. Documents have included questions as headings in Arial size 14 and the participant's response Times New Roman size 12 prior to importing into NVivo for data analysis.

Where a response to open ended questions was not supplied, a space has been left to signify a lack of participant response. Where there has been incorrect spelling used by participants, the participant's spelling has been corrected to enhance data analysis. In the event of the participant's hand writing being illegible recognisable letters have been documented.

## **Emic position**

As a researcher I will need to be mindful that as an experienced renal nurse I must be aware of my preferences such as what do I want or what do I expect to find. As Gillham (2000) suggests these preferences, can be worse than my prejudices of what I think or what it is all about and suggests although these are not necessarily wrong, they may be based on insufficient evidence. My reflections associated with my own perceptions as an experienced clinician, I needed to record through my reflective journaling and although it may be impossible as a researcher to maintain absolute

objectivity, at least I should 'strive for a level of detached honesty' (Gillham 2000, p. 28) as a way of acknowledging my own place in the process of the research.

## **Data analysis**

### **Qualitative analysis**

The qualitative analysis process was guided by Braun & Clarke's (2006) six phases of thematic analysis as described below. Braun and Clarke (2006) recommend that the content analysis, phase two, is completed prior to the thematic analysis, phase six. Results of phase two the content analysis being presented in Chapter Five are then followed by the results of the thematic analysis as presented in Chapter Six.

Braune and Clarke's six phases of thematic analysis:

Phase one: Collating and familiarising oneself with the data set.

Phase two: Systematically rechecking and coding of the data into thirteen concepts.

Phase three: Searching for themes.

Phase four: Reviewing themes.

Phase five: Defining and assessing if themes represented the data set.

Phase six: Producing the report of the thematic analysis.

A content analysis of the data utilised these initial two phases, by transforming the qualitative data into a formalised table that allowed the text fragments to be grouped. The second phase included familiarisation with the participant responses and systematic coding of the data. An all-inclusive method was applied to the analysis of the qualitative data to where open ended questions from all participants i.e. patients, family/carers and staff members, were analysed as one data set. By

collapsing participant responses to the open ended questions similarities and differences in the responses between the participant groups were evident.

The content analysis which led to formalising 13 concepts informed the thematic analysis. This analysis method was designed to elicit salient themes from the participant responses to the semi structured questions. Themes were created based on the frequency, saliency and nature of the responses, identified through the content analysis and the theoretical perspective underpinning the study. Through utilising the Bioecological Theory of Human Development four constructs of process, person, context and time (PPCT) as a means of collating the thematic analysis results, it was found that the PPCT model resulted in illuminating greater depth and meaning during the analysis of the qualitative data, through relation of the emergent themes to a theoretical base.

### **Quantitative data analysis**

The study design included a minor quantitative component. The quantitative data analysis was limited by small group sizes of each participant group to non-normative analysis. No comparisons to external groups are feasible with the limitations of the sample size. The research question 'What bioecological factors influence the outcome of care of patients' vascular access for haemodialysis treatment?' was explored through correlations between the independent and dependent variables arising through the instrumentation. Correlation coefficient was the primary effect size index utilised to evaluate associations between the independent variables measured through the family satisfaction scale, the family strengths attributes scale and the patient empowerment scale and the dependent variables measured through the SF-

36v2®. Numerous associations were explored through correlation coefficient's (see Appendix 14. 'Non-parametric correlations' for the results of these associations').

When data can be ordered in a meaningful way, it is ordinal and therefore non-parametric. Non-parametric test for correlation include Spearman rank order correlation or Kendall rank coefficient of concordance (Field 2005, p. 129). Salkind (2010) recommends Spearman rank order correlation when data sets contain a large range of values and reduced frequency of tied ranks. Kendall rank coefficient of concordance is the recommended test when there is a small data set and many scores have the same rank (or value) (Field 2005, p. 131). Kendall rank coefficient of concordance is often used with data sets involving  $n < 20$  (Legendre 2010).

The collected empirical data allowed for relationships between covariates associated with patient wellbeing to be explored. Field (2005, p. 123) advocates the use of 1 tailed test when directional predictability is theoretically supported by the descriptive theory. The descriptive theory of this case study has informed the decision to use 1 tailed test of significance. Caution in interpretation of causality from correlation coefficient is required (Field 2005, p. 127).

Effect size (power) for the study was determined from published standards of effect in healthcare research. The effect size however, of the strength of the relationship between two or more variables can be estimated from the correlation coefficient (Field 2005, p. 32). Effect sizes have practical importance in that they are resistant to the influence of participant sample sizes and therefore utilised to provide an 'accurate measure of the magnitude of effect between variables' (Kobayashi et al.



2014, p. 9). Interpretation of correlation coefficient of .5, .3, and .1 can be regarded as large (or clear), moderate and small respectively (Meyers et al. 2006, p. 115).

Determining effect size follows the logic that if a big effect is expected a small sample size is required as opposed to where a small effect is expected, a larger sample size is required (Field, 2005). Thus a greater power would require a larger number of participants. It is important as an experienced clinician to determine the clinical meaningfulness of this power for example, change in the individual's life. Therefore interpretation of the power of the study results, is in looking at how likely would these results have been what was expected, in this case above medium (0.3-0.5) being not completely obvious however, they were not too difficult to detect. Utilising Spearman's correlation coefficient to determine the effect of potential associations of interest in this study provided a guide to interpretation of correlational analysis results.

## **Administration and instrumentation**

A self-administered questionnaire was distributed to the potential participants of the CS. The SHDU Nursing Unit Manager (NUM) provided eligible-potential participating patients, family/carers and staff members with the relevant questionnaire and information sheet. The SHDU-NUM collected the questionnaires which were safely stored in a central location which was to ensure participants' anonymity. Three different questionnaires were distributed depending on the grouping of the participant being patient or family/carer or staff member. Each questionnaire contained both open ended questions designed to collect qualitative stories and numerous quantitative questions as described below.

The healthcare professional's questionnaire consisted of five open ended questions (see Appendix 9. 'Site Specific Open Questions for Healthcare Professionals'). The family/carer questionnaire consisted of three open ended questions (see Appendix 8. 'Site Specific Open Questions for Family Members or Carers'). The patients' questionnaire consisted of seven open ended questions and sixty Likert scale questions (see Appendix 7. 'Site Specific Full Survey for Patients'). The Likert scale questions were constructed from three published scales: SF-36v2® (Ware et al. 2008) which reports two subscales of Physical Component Scale (PCS) and the Mental Component Scale (MCS); family satisfaction scale (Olson et al. 2006) and family strengths attributes scale (Smith et al. 2013). These scales were supplemented by questions developed from the literature that were constructed into the patient empowerment scale. The wellbeing measures embedded in the questionnaire were the two subscales contained in the SF-36v2®, PCS and the MCS.

## **Construct validity of instrumentation**

The validity and reliability of the different scales within the questionnaire are presented below.

### **1. SF-36v2®**

This measure is a 36 item self-report instrument used to measure aspects or domains of an individual health status (mental and physical health), which has been divided into eight domains. Permission to use the full tool was gained for the utilisation of this instrument. These domains of one's health are considered to be important in monitoring and describing the individual who is suffering from a disease-illness. As a self-reported survey, the SF-36v2® was not intended to be completely

comprehensive it is intended to measure the domains of one's functioning, which in principal represents the individual's behaviour.

This tool reports two sub-scales; the Physical Component Scale (PCS), and the Mental Component Scale (MCS) which were derived and scored through utilising a factor analysis method of principal components analysis, of the two broad aspects of one's mental and physical health. These two components are divided into eight health domains including physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, mental health and reported health transition.

All participating SHDU patients' responses to the questions within these eight health domains scales were then collated from each participating patient's questionnaire of 36 items, which were then scored electronically, but for the exception of item 2. health transition, which was not utilised to score any of the health domains or the participant component summary measure. Through the utilisation of these component summary measures, the patient's physical and mental self-assessment of one's health was revealed, at that point in time. A strength of the PCS and MCS measures is a value that enables the researcher to compare these two components—health domains, and distinguish a physical health outcome, from a mental health outcome (Ware et al. 2008).

The construct validity of the SF-36v2® has been demonstrated to be maintained during the CS however, as Ware et al. (2008) advice construct validity of an investigation, can depend on the context in which this tool has been administered. Following the SF-36v2® instructions, had facilitated the utility of this tool and

removed the risks of compromising the validity of the results. Checking for construct validity of the results of the SF-36v2®, as a whole had included examining the patient's responses to the questions as an individual, as well as across the entire participating patients' group. The qualitative evaluation of the data quality was established by examining the data for examples of incompleteness and inconsistencies. Data quality evaluation of individual health domain scales was examined on a scale-by-scale basis by assessing the completeness of the data (quality) as a whole.

## **2. Family satisfaction scale**

The family satisfaction scale (FSS) is a 10 item scale assessing family satisfaction, cohesion, adaptability and communication are all important dimensions along which family functioning is characterised (Koutra et al. 2013). Koutra et al (2013) explains, family functioning refers to the quality of the family members' interactions. This CS utilised the FSS as these ten questions (items) related to the patients' experiences and perceptions, involving their family members which focussed upon the patient relationships with their family. This current 10 item scale was included as one of a six-factor scales within the well-known FACES IV (Olson et al. 2006). The FACES IV six factor structure, includes two balanced scales of Balanced Cohesion and Balanced Flexibility, as well as four unbalanced scales of Disengaged, Enmeshed, Rigid and Chaotic (Koutra et al. 2013). It is designed to capture the high and low extremes of cohesion and flexibility as it investigates both balanced (healthy) and unbalanced (problematic) aspects of family functioning, as well as balance within the family

functioning (Koutra et al. 2013). Koutra et al. (2013) report the FACES IV has been shown to have satisfactory utility in both internal and test–retest reliability.

The FSS was originally developed by Olson and Wilson (1982).

Correspondingly Olson et al. (2006) have reported alpha reliability of .92 and a test-retest reliability of .8. These results have been supported by Underhill et al. (2004) through their report of an internal reliability of a modified FSS with Cronbach's alphas of .94 at 12 months and .95 at 60 months. These results are comparable with the original alphas at .92, having a test-retest reliability of alpha .75 at five weeks (Olson & Wilson 1982). Underhill et al. (2004) results from their study of individuals who had survived traumatic brain injury, supported the validity of the FSS, through an internal consistency reliability, demonstrated as Cronbach's alpha for the FSS at 12- and 60-month as .94 and .95 respectively. Koutra et al. (2013) having completed a cross-cultural adaption of the FACES IV from English to a Greek version, have reported displaying a similar factor structure to that of the original FACES IV version by Olson et al. (2006), by once again having revealed satisfactory results, reporting that both their adaption and the standardization of the FACES IV to be robust and flexible.

### **3. Family strengths attributes scale**

The family strengths attributes scale (FSAS) explored participants satisfaction of family strengths as displayed by members of their healthcare team professionals towards them, which was assessed through six questions based on the international family strengths model by DeFrain and Asay (2007). A higher score indicates the more satisfied the participant is with the expression of family strengths amongst the healthcare staff members towards them as a recipient of healthcare. This tool was

first reported by Smith et al. (2013) and has good construct validity due to the well-established evidence and literature published on the international family strengths model. Although this scale has construct validity, there is no reported reliability statistics. The original study called this scale CFS and with the permission of the developer of the scale (Smith 2011) this scale has been renamed as FSAS for this CS. In this study, the FSAS was utilised in relation to patients' perceptions of their healthcare; hence, the identifier of healthcare professionals (HCP) is included. As this scale had now evolved it had become the FSAS-HCP scale and is a new and therefore previously untested scale. The FSAS-HCP scale, included six questions that represented how satisfied the patients' felt from their experiences and perceptions of traits embedded in the care of healthcare professionals as members of the patient's healthcare team, from a family nursing perspective.

#### **4. Patient empowerment scale**

Following an extensive literature review to complete the descriptive theory for this CS, it was identified that no suitable scales relating to empowerment were readily available. Morris et al. (2014) refers to Israel et al. (1994) as explaining that empowerment represents the process of increasing one's sense of control over the decisions in their lives thus, enabling the individual to take actions that are personally relevant to their life and treatment goals. Current empowerment scales identified, were too extensive for inclusion in this study and/or specifically related to another area of health care. As an example the Empowerment Scale by Morris et al. (2014) is designed to evaluate the differences, when utilising an Empowerment Scale between two different cultures of people experiencing severe mental health conditions.

The Patient Empowerment Scale (PES) included five questions representing the patients' reported perceptions of one's empowerment at that point in time. Construction of the open ended questions were included in the participant questionnaires as a form of inquiry that can be utilised to delve for more sensitive and or stigmatising information, for example why patients find it difficult to manage and or adhere to scripted medical treatments (Friborg & Rosenvinge 2013). Studies that have utilised mixed methods including open ended questions for example, exploring the differences of why some people cope-manage better than others when faced with living with stressful and dismal situations (Morris et al. 2007), have provided considerably rich knowledge from the responding participants' experiences. Therefore the sentence structure and terminologies of the open ended questions, were written so as to support participants to respond to questions (uninhibited through their anonymity) to reflect upon one's wellbeing, in relationship to their personal experiences and perceptions. Through utilisation of these open ended questions, the results have provided more in-depth information, by uncovering tentative explanations of human motives and experiences, behind the established phenomena (Friborg & Rosenvinge 2013).

## **Purpose of instruments**

The questionnaire construction was guided by the theoretical model underpinning the research study and the findings from the descriptive theory, articulated in Chapters Two, Three and Appendix 2 'Understanding the journey travelled by patients and carers living with end stage kidney disease and haemodialysis.' The qualitative questions (see appendix 7, 8 and 9 Full Questionnaires) were developed to explore

the research question from the perspective of the three participant groups. The term wellbeing was used consistently across the three participant groups open ended questions to provide data that could triangulate the concept from three perspectives. These questions were reviewed by the research team and the SHDU Nurse Unit Manager for relevance and fit-for-purpose with the patients and family/carers of the SHDU.

The full version of the SF-36v2® standard Australian (English) version was selected for its validity (See p. 99 Administration and Instrumentation) and wide acceptance in the Australian healthcare sector (Hawthorne et al, 2006). The SF-36v2® supplied program for analysis of the raw data was used. This analysis is based on the International normative data and not the published Australian population normative data. Hawthorne et al, (2006) recommend to help avoid misleading estimates of outcomes use of the Australian population normative data for analysis when the local outcomes are compared to expected outcomes between countries or communities and when there is reason to suspect local outcomes reflect variations. This research project scope excludes SF-36v2® outcome comparison and the use of the International normative data for analysis was suitable.

The SF-36v2® measure outcomes of healthcare across two domains of wellbeing—mental and physical—that were utilised to explore associations with the independent variables measured through the family satisfaction scale, the family strengths attributes scale and the patient empowerment scale. Associations were explored through correlation coefficient's with a p value of <0.05.

## **Assumptions**



This CS utilises a naturalistic approach to exploring the proximal processes while maintaining a focus on what influences the care of a patient's VA for haemodialysis. A naturalistic approach allows participants the freedom to express their own experiences and perceptions. Both qualitative and quantitative data analysis explores patterns for further descriptive theory. The participants may potentially share common experiences, perceptions and care/outcomes of care. This CS is not representative of the broader populations of patients and their family and or friends as carers living with ESKD and haemodialysis while relying on the viability of the patient's VA to survive. Nor does this CS represent healthcare professionals experience and perceptions within this SHDU, of the much broader world by their participation in this CS. This CS does not attempt to investigate worldwide experiences nor perceptions of this group of people more so, this CS represents one SHDU community as participants respond freely (in anonymity) to their experience and interpretation of those experiences, at that point of time.

## **Description of the case**

For patients with ESKD requiring haemodialysis the continued patency of their VA is vital for their haemodialysis as a RRT. Differing cannulation techniques and nursing management of VA care can result in the patient experiencing pain and fear of their AVF or AVG while being at increased risks of complications (Koncicki et al. 2015; Dinwiddie et al. 2013; Van Loon et al., 2009; Ball 2005; Brouwer 2005). The nursing management of a patient's VA requires optimal techniques of cannulation and implementation of evidenced based practice guidelines to maximise the patency of the patient's VA. Nursing research is required to help further understand the

bioecological factors of a patient's VA outcomes and to develop clinical guidelines for nursing practice that incorporate quality of life considerations of the patient, family and friends as carers alongside minimisation and early detection of VA complications.

The process of collating participant data i.e. patients, family/carers and staff members responses to the open ended questions was by entering the data into a formalised table (see Appendix 13. 'PPCT model: 13 Concepts, text and terms employed by each group'). This simplified the process of identifying texts and terms contributed to the CS by an individual, a group and or across the entire data base of participant responses. The content analysis followed Braun & Carke (2006) in utilising the first two phases of their six phase thematic analysis.

The first phase was familiarising oneself with the data. The second phase was a systematic coding of the data through a progression of collating clusters from the entire data set. Looking at the research questions and participant responses in their entirety and then collapse them, developing groupings among participant responses which were found to be the most common among the entire data set.

The second phase of coding data had included the first step of identifying "key words" within their context. Subsequently the second step was in further development by identifying "key terms" from the patients, family/carers and staff responses. The result of this reiterative process of evolving coding and edifying corresponding features became illuminating as 13 groupings of content were established as concepts.

Key words and terms employed by participants in their responses, as 13 concepts aligned with Bronfenbrenner's theory of bioecological model of process, person, context and time (PPCT). The full table of results of the content analysis is included in Appendix 13. 'PPCT model: 13 Concepts, texts and terms employed by each group'. The key terms for each concept have been listed at the start of each concept. The thirteen concepts are presented in the rest of this chapter.

## **Ethical considerations**

An initial meeting was held in March 2013, where present were my higher degree research (HDR) supervisor Associate Josephine Chow and Doctor Michael Suranyi as Head of Renal Services of the South Western Sydney Local Health District (SWSLHD) NSW. One of the SHDU communities within this Renal Service was to become the case for this research project. Doctor Suranyi provided a letter of 'Approval to proceed with the Research Project' (see Appendix 10. 'Authorisation from the SWSLHD Director of Renal Services as Delegate of that Site'). After which a Tasmanian ethics application of a 'low risk' single center SHDU application for the CS was submitted to the Human Research Ethics Committee (Tasmania) Network and was approved on 31 October 2013 (see Appendix 11. 'Human Research Ethics Committee (Tasmania) Network'), as the University of Tasmania is based and of which I am a student. Once the Tasmanian ethics approval was received, a second ethics application was submitted to the Research and Ethics Office, of the South Western Sydney Local Health District Human Research and Ethics Committee, as a 'low risk' single center SHDU for this CS, their approval was provided on the 26

March 2014 (see Appendix 12 'South Western Sydney Local Health Research and Ethics Office'), as a 'low risk' single center SHDU research project.

In June 2014, an introductory meeting was held with the nurse unit manager (NUM) of the SHDU, the acting NUM and key staff members within this community, to explain both the purpose and process of this CS. During July 2014 the SHDU-NUM distributed information sheets and made available the questionnaires to potential participants. The information sheets and questionnaires were distributed as non-identifiable documents. It was not appropriate or intended within the parameters of this CS to collect identifiable data, for example staff member positions in this single center CS. As the SHDU-NUM had taken leave one week after distribution of questionnaires, the acting SHDU-NUM collected the participant questionnaires after a two week period allowing participants time to complete the questionnaires.

Questionnaire distribution allowed anonymity of participants. Anonymity was important to maintain over confidentiality, as such the questionnaire method was appropriate to collect anonymous data. The questionnaires were transferred to electronic documents. Quantitative data was collated into a word document and qualitative data was collated onto an EXCEL spreadsheet. Original questionnaires were stored in the office of the Principal Investigator at the University of Tasmania. Electronic data will be kept in a password protected file on a secure University of Tasmania server, accessible only by the investigators.

During the course of the study, the non-identifiable data was stored on a password protected computer and in a locked filing cabinet in the office of the Principal Investigator at the School of Nursing and Midwifery University of Tasmania. The original questionnaires were shredded and electronic data will be permanently deleted from the computer by an IT administrator five years after first publication as per University of Tasmania HREC and NR & MRC guidelines.

## **Trustworthiness**

There are a number of advantages of CSs when utilising a mixed methods approach to data collection, management and analysis. A mixed methods approach to this CS included three sources of data from three groups of participants i.e. patients, family/carers and staff members (healthcare professionals) and both qualitative and quantitative data and analytic methods thus enabling triangulation of results.

Triangulation of mixed sources of evidence provides a cross-validation to complement the individual findings and can enable the CS researcher to harness a multitude of selections between and from data sources and within quantitative and qualitative research methods (Torrance 2012; Yin 2009). As a metaphor, triangulation has been adopted from navigational disciplines. Gillham (2000) explains that triangulation provides a point through which all lines or mixed data sources converge to agree and if not to disagree and as such, the nurse researcher might consider how the comparative CS may relate to the research question. Triangulation proposes a search for regularities or irregularities and to 'the degree to which findings are mutually reinforcing or irreconcilable' (Bryman 2007, p. 21). By utilising a mixed

methods approach for this CS it had provided the forming (or negotiating) of an overall account of the findings by bringing together the components as though they were conversations or debates.

## **Conclusion**

Confusion and debate may remain in whether a CS in research is a methodology, method, design or strategy which can be attributed to inconsistencies in the utilisation of CSs and their report. Coupled with this is the continual poor reporting of CSs in nursing texts and in peer reviewed journals adding to the debate about the trustworthiness, validity or rigour of CSs. The one point that does appear to be gathering consensus is that a CS methodology is a comprehensive research strategy which can be a practical and appropriate approach to research for nursing both in practice and as a researcher. CSs in nursing research are gathering in appreciation, enjoying a renaissance which may be attributed to their successful application to real-life phenomena and therefore, increasingly counteracting criticisms of CSs right across the social science disciplines. CSs have an inherent flexibility useful and practical to nurse researchers and can be particularly useful for nurses undertaking research from novice students to expert researchers, especially those working in rural and remote areas of Australia.

The contribution that CSs have to nursing practice is in their ability to extend nursing knowledge and provide support to the on-going development of EBPs to deliver improved patient health care outcomes. This is particularly relevant when utilising a CS methodology that incorporated a mixed methods approach for this research project. Collation of multiple data sources and methods of analysis including

utilising triangulation of data can provide nurse researches with more nuanced understanding of the phenomenon under inquiry. Utilisation of a mixed methods approach to CS research can be of great consequence when addressing issues relating to marginalised groups such as people living in isolation for example, rural or remote communities and or individuals who are living with chronic illnesses, such as ESKD requiring chronic care.

A case is not discovered, it is a contemporary phenomenon within the real-life context waiting to be investigated. Writing up a report of the journey and outcomes of a CS, is inarguably the most important role. Writing requires meticulous detail to ensure that the report of the CS is a compelling report or book, intended to optimise the audiences' understanding of the case in its context and the issues under inquiry, through the utilisation of a CS methodology which incorporates a mixed method, aligns as the third paradigm.

In this CS there is a rationale that by utilising a methodology of mixed methods of qualitative, with a minor quantitative component, it is the appropriate methodology to investigate the care of the patient's VA in this SHDU environment. As a CS, this investigation is of the case of a SHDU community, as an interactive system of the ecology being a comparatively stable environment. In reality this case, is a closed system where the phenomena is quite evident and is not confounded by external forces. As opposed to other hospital ward environments, which are influenced by external forces, more likely to occur for example in surgical wards, where generally there are more transient populations of patients and their family/carers. It is anticipated that through the writings of this dissertation, the experiences of this

vulnerable and often marginalised population, will result in translation of knowledge to the audience. Resulting in a greater understanding of patients and family/carers experiences of living with ESKD, co-morbidities and regimens of treatments including haemodialysis therapy requiring the longevity of a viable VA for the patient's continued survival.

The complexity and chronicity of the lives of patients living with ESKD includes multiple influences on their development and outcomes, such as co-morbidities, treatments including haemodialysis therapy requiring a viable VA and promoting longevity of their VA. The CSs qualitative enquiry included within the questionnaires utilises disease specific open ended questions relating to the patient's wellbeing. The utility of the bioecological PPCT model played a key role in organising this CS's qualitative data in a more meaningful way to understand the patients', family's/carers' and staff members' experiences and perceptions.



## **The story continues**

There is a school of thought that believes research paradigms can be methodological in their foundations (Freshwater & Cahill 2012). Mertens (2012) proposes however, this concept will only serve to falsely label the three paradigms, which instead are more closely aligned to qualitative methods, quantitative methods and more so in more recent times, scientists have credited the union of quantitative and qualitative in forming a mixed methods approach as methods vary in data collections and are not epistemologies, methodologies, designs, nor are they ontological suppositions readily combined with different research outlines. Mertens (2012) proposes that by taking this dialectic stance, it affords the researcher to be situated as adhering to the belief that in conducting data collection as quantitative-orientated, by their adherence to beliefs of a post-positivist paradigm whereas qualitative-oriented being the constructivist paradigm.

As utilised in this case, a mixed model method can facilitate a good CS and as the nurse researcher, similarly to Mertens (2012) proposed, I was able to take a dialectic stance of welcoming more than one paradigmatic tradition and introducing the two paradigms to engage equally into a conversation as a continual respectful dialog throughout the CS. As the researcher however, I needed as Gillham (2000) has suggested through my reflections on my personal position within the research, that I maintained my position of detached honesty. Therefore, by acknowledging my own prejudices of preconceptions and expectations during the process of the research to present a true picture, otherwise the trustworthiness and validity of this CS may have been compromised. I needed to avoid the compulsion to tidy up the

results as Gillham (2000) suggests such as to assemble it to be more presentable. As this CS was a reflection of real lives and therefore, seldom presents a tidy story.

Research projects such as this CS, may not interest every nurse as they are often busy, juggling demanding full time positions and can frequently be travelling long distances in their everyday work. Research projects take time, money and resources (Brophy, 2008; Keyzer, 2000). This can be a problem particularly for rural or 'outback' nurses who are often employed in remote areas. Taking on further education and research studies can prove to be a dilemma for some nurses particularly when they are somewhat isolated from the urban based academic centres (Keyzer 2000).

In my own experience while studying as a 'distance student' completing my dissertation and working within the renal services within a rural community, clinical nephrology (renal) nurses have initiated a variety of quality improvements (QI). Utilising evidence uncovered in the literature and or presented at conferences, to establish changes by implementing EBPs and through nurses', patients' and family's/carers' skills, education, opinions and preferences as a continued process of evaluation adaption to changes, in our real-world health care clinical settings (Melnik et al. 2014). Some of these QIs which I have been involved in during the last six years, include patient and family/carer health care educational projects, VA monitoring and surveillance programs and "green dialysis" by initiating practices and implanting community traditions that make dialysis treatments and product waste disposal methods more eco-friendly.

Chapter five will continue the story of the CS project, as it presents the case and the purpose of this study, the analytic processes of the case's qualitative data content analysis, which follows the first two phases of Braun and Clarke's (2006) six phases of thematic analysis. Phase one included collating data and familiarising oneself and recording potential coding of the data. Phase two was a process of systematically rechecking and coding data, ongoing process where the coding of data became thirteen concepts.

Chapter six is the thematic analysis which continued Braun and Clark's (2006) steps, with phase three by searching for themes. The forth phase included reviewing these seven key themes. The fifth phase was a process of defining and assessing if the themes represented the data and the sixth phase was producing the report of this thematic analysis. Triangulation of results was achieved with the thematic analysis completed it was then followed by a minor component of quantitative analysis.

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## **CHAPTER FIVE: RESULTS OF CONTENT ANALYSIS**

### **Introduction**

Chapter five presents the results of the case study (CS) content analysis which then moves forward to Chapter six, the thematic analysis results. These two chapters follow Braun and Clarke (2006) process of a six phase thematic analysis. Importantly, although both analytic processes are qualitative, the difference between a content analysis and the thematic analysis is that the content analysis focuses on the fragments within the data, while the thematic analysis focuses on the connections within the data.

### **Participants**

A total of 54 participants completed the self-directed group questionnaires for this CS. There were three groups of participants within this SHDU community. The first group of participants were 32 patients who were living with end stage kidney disease (ESKD) receiving haemodialysis therapy requiring cannulation of their VA of autonomous arterio-venous fistula (AVF) or synthetic arterio-venous graft (AVG). The second group of participants were 8 patient family members or friends which are represented as carers. The third group of participants were healthcare professionals a total of 14. These are the cohort of participants from which the content analysis was completed.

### **Content analysis of the qualitative data**

## **Process**

### ***Comfort and acknowledge***

Care/look after, intervene, resolve, cater for, accommodate, needs, flexibility, support, assist, help, encourage, reassure, communicate, converse, chat, talk, listen, interact, acknowledge, comfort, compassion, thoughtful, attentive, friendly, kind, safe, protected and belonging:

This group of content conveys the concept of patient comfort and being acknowledged as individuals with their own needs and as a consciousness of caring. Either as receivers or in the role of care providers (care givers) the staff members and the patient's family/ carers i.e. their family members and or friends. There was a strong focus of ensuring the patient's comfort. The concept of comfort (comfortable) and being acknowledged is aligned with enabling the patient, through their reciprocal interactions over time, i.e. between the individual and their immediate external environment (Rosa & Tudge 2013). The individual can develop and become empowered through reciprocal interactions within the SHDU community. Through effective communication and respect that supports a patient's perceptions of belonging, rather than a single element of caring i.e. where one's role is restricted to comforting the patient, which is more in line with sustaining one's ability to cope, rather than comfort and being acknowledged as a person, enabling the individual to cope and adapt (Bayaumi 2012), as a progressive development over time. The concept of comfort and being acknowledged was demonstrated by positive orientated texts and terms, embedded within participant responses across all three groups.

Participants had employed these texts and terms most recurrently throughout their responses i.e. 152 texts and terms in total.

**Patients** had reported 'Being able to communicate' (P24) and similarly 'Communicating preferences and problems' (P17) and engaging in 'Assertive communication with staff' (P9). Communication was thereby reported as an important factor for an individual's interactions with their environment. One patient replied that their ability of 'looking after myself and others' (P25) was important to them. While another patient had shared that as a result of the care they received from staff members, they had been able to regain energies that had been lost and as a result of the care they received, this had enabling them to achieve their goals by being more active in their daily living, responding 'Thanks very much' (P23) to the staff members. Family members in their carers' roles had received praise from the patient for being supportive 'my daughter and my carer (daughter in law).'(P10). Patients were encouraged to take part in socialising within the SHDU community and in doing so, reported experiencing feelings of belonging. This was exemplified by a patient who shared 'Sometimes the nurse spends ten minutes with me to watch TV, it makes me feel like they care and belonging because we laugh together.' (P8). Another patient reported similar experiences of the '(nurses, students, other clients) they are all my family and friends' (P14).

**Carers** had shared their experiences and perceived responsibilities as the patients' carers, with dominant terms such as help, care, look after, support and encourage their loved ones as patients. Carers conveyed their methods which they had used to support patients, revealed shared familiarities among their immersion

into caring for their loved one in their daily living both in the home and in clinical environments such as the SHDU community. This was exemplified by one patient's carer as 'Listening to their concerns' (CR3). Carers communicated compassion in their role as care providers 'my mother's wellbeing is of utmost importance to me. After all, that is part of my duty of care, to keep her as comfortable, healthy and happy as possible.' (CR6).

**Staff members** reported they encouraged patients and their carers to feel they were acknowledged when attending the SHDU community during their regimen of haemodialysis therapies, necessary for the patient's survival. Staff acknowledged the patients and carers individual needs. One staff member reported they would have conversations with patients to assess if they 'Were happy' attending this SHDU community and that they felt they could share their concerns with staff members and were their 'needs met' (S4).

Another example of maintaining patient comfort was that staff had maintained a degree of flexibility in regard to patients appointment days and times. Staff members had received praise for organising scheduled care to allow for patient and carers needs. An example of this was when a patient's daughter expressed their gratitude for the staff in thanking them for the care and consideration they had given to both the patient and their family after the death of a family member, 'thank you for looking after mum' (S4). Staff members encouraged patients to attend appointments as well as 'important events' to continue their 'social interaction' (S3) with family and friends, and the larger public community. Staff members shared their values which had been reported were embedded in the care they provided to promote patients



(and carers) 'being positive and having a sense of encouragement' (S10). By the same token staff members had retained a 'Positive attitude toward patient care promotes positive outcomes to patient's'. (S3).

The concept of 'comfort and acknowledge' conveys the essential element of caring. Human development of patients, carers and staff members takes place through regular interactions as processes become more and more complex in reciprocal interactions with their environment over time (Arnold 2012). There was a significant grouping of content relevant to this concept across all three groups of participant responses. This concept symbolises a model of "caring", enhanced moreover by a helpful, caring and supportive attitudes which were conveyed throughout patients', carers' and staff members' responses. All participant groups frequently conveyed that care needed to be delivered with assertive and effective communication. Staff members and patients' carers had revealed strength in these values, being embedded into their roles as care providers or more aptly care givers. These values found to reassure patients (and their carers). Acknowledgement of patients and carers needs had been demonstrated by the staff and carers, reporting the necessity for and value of flexibility. Encouraging patients with culturally sensitive attitudes addressing both the patients' and their carers' needs.

### ***Being loved***

Family, partner, husband, wife, daughter, son, sister, children/grandchildren and or friends (and as carers) including the SHDU community other patients and carers:

This grouping of content demonstrates the concept of "being loved".

Predominantly this includes patients' family members and friends. Patients had

reported they had developed bonds with the other patients, carers and staff members in the SHDU community. As patients had described as part of their life's journey their bond of being loved and caring about 'family and friends' (P14). The community within the SHDU had been included in the concept of being loved.

**Patients** had shared their experience of gaining comfort from the love they had received from supportive family and friends. This concept of being loved was reported as having helped patients to achieve a satisfactory level of wellbeing. As one patient reported 'Good health being able to socialise with friends.' (P24). Similarly another patient responded their wellbeing was achieved by being able to 'Pop into my friends place for a coffee and a chat, helps me feel good.' (P5). Similarly another patient had responded 'Catching up with old friends.' (P28). As such, this concept of being loved and the comfort received from one's family and friends was reported to be central to a patient's needs.

A patient had shared the importance of the basic human need 'To be loved by my children and their families' and to have supportive 'friends' (P23). Similarly another patient had praised their family by recounting 'My family are so supportive' (P10). Another patient had shared 'Good wellbeing. Support of family and staff.' (P8) was important to their enhanced wellbeing. Therefore patients' and their carers' roles, were reported as being enhanced by the friendships and bonds they had formed with others within the community of the SHDU. Patients and carers through being encouraged by staff members to socialise shared a bond through their common health journeys and regular attendance in the SHDU community. A patient expressed the significance of these friendships and the happiness they felt within the SHDU

community by sharing 'everybody here' was to this patient like 'family and friends' the patient reported had made them 'very happy.' (P14).

**Carers** had illustrated within their responses the importance of showing compassion to their loved one. As one carer related, they had felt that it was important for the patient to 'make them feel special' (CR5). One other carer had shared 'Assuring her of the love and compassion we as her family have for her no matter what' (CR6). Another carer recounted how the staff had supported their mother as a patient, when this patient's mother (carer's grandmother) had passed away. The staff had accommodated for this patient's and her family's needs such as, changing treatment days and times allowing for the patient to attend church services held over several days. The patient's son as a carer for the patient expressed the level of support the staff members had delivered. The carer described the attitude of staff towards patients and their families as 'They also always care so much for them in dialysis and are nice and friendly. This uplifts them and encourages them' and reported that the staff members 'sent a card for mum and family to comfort us in this sad time.' (CR6).

**Staff members** reported supporting patients during their time spent at the SHDU community and in some instances in one's home or in social matters. Patients and carers, such as family members required the support of the staff members for social issues outside the SHDU community. An example of this was shared by a staff member in relation to a patient and their family needs 'A patient had personal problems where he had split from his partner' and his 'Daughter approached me if I

could help in any way. Patient was referred to the social worker and now we have provided him with ambulance transport and is much happier and settled.’ (S9).

This grouping of content encompasses the patients family members and friends, including friendships formed within the SHDU community, as a result of the patient attending for their haemodialysis therapy. Processes effecting one’s development can vary with the nature of the person, their environment (immediate and remote) and social continuities as well, change over time (Tudge 2009). Social continuities were reported as exemplified by the concept of “being loved” by family and friends. As a process of human development participants reported feeling loved, by providing examples of actions taken by family and friends that displayed emotional support of their loved ones. Participants had responded by illustrating the art of caring and caring about someone, caring for a loved one and this love being reciprocated. The concept of being loved is an important element in one’s care and development.

### ***Knowledge and rights***

Knowledge, inform, guidelines, safe practice, recommend, involve, sharing, told, advise, educate, learn, teach, instruct, addressed, discuss, explain, understand, rights, choice, options, beliefs, culture, values, preferences, decision making, refuse, consent and goals:

This grouping of context represents the concept of “knowledge and rights” empowering patients and carers. Through health care education, patients and family/carers acquired knowledge. Respecting patients’ and family’s/carers’ wishes and their rights to have a voice in decision making, involves proximal processes in

progressively complex and reciprocal regular interactions within their immediate environment over time (Bronfenbrenner & Morris 1998).

**Patients** reported being educated about their disease process and treatments including haemodialysis. The timing of education was an important factor, as one patient responded they would have liked to have had more education earlier in their care, in regards to their VA and health care treatments would have included 'Education of dialysis. Benefits of dialysis' (P13). One other patient responded that receiving information concerning their health care was important 'Because I have a right to know every treatment' and 'to refuse the treatment' and it was better to have had this knowledge about their 'treatment before starting.' (P22). Another patient responded that the staff members were mindful of their wishes as they would 'provide an excellent care' which was 'According to my choice and comfort' (P26). Similarly, another patient responded their understanding of importance to having valuable health care education 'Learning more, importance of my dialysis and its value to my health and to stay healthy.' (P25). Correspondingly, another patient responded this was important to 'Maintaining my dignity.' (P29). These elements were reported as being essential to the patients' care.

**Staff members** reported they had promoted patient goals by providing patient care through a strong effective team. One staff member responded 'sharing of information' (S6) was important. Staff members had been compelling in their responses that embedded in their objectives was the importance of empowering patient and carers by involving them in the patient's health care and education prior to commencing their initial haemodialysis treatment and to ensure they are part of the

'decision making.' process (S12) regarding the patient's health care choices. One staff member explained 'We are here to support patients, carers and educate them' (S9). One other staff member pointed out, that it is important that the members of the patient's health care team 'have sufficient knowledge and education to care for the patient' (S13). Another staff member explained 'The healthcare team are very influential in a patient's wellbeing'. (S6) and 'Education is what patients need to promote self-care' (S3). Enabling the patients to self-care required providing information to enhance 'patient knowledge, involvement and encourage self-care in the unit' (S4). Another staff member responded that a patient has rights and they are an important element of care giving, through effective communication, patients are 'being heard as a person' (S11).

This group of content relates to patient and carer empowerment, as a concept of "knowledge and rights" revealed by participants, as an essential element in the enhancement of both patients and carers meeting their goals. Patients and carers directly expressed their need to have a voice and to have the knowledge to enable them to make informed decisions concerning a patient's care planning for their health care pathway. Patients, carers and staff members recounted the importance of shared knowledge that promoted patients' and carers' empowerment. Staff members, carers and patients responded that patients and carers required respect, dignity and trust, and that care was provided by staff members possessing a thoughtful and caring attitude. Staff members, patients and carers had addressed the rights of the patients and carers to be treated respecting their culture, dignity, integrity, beliefs and

values. Hence, patients and carers were to have a voice in decisions made about the patient's care and to be treated as members of their healthcare as part of "the team".

### ***Hygiene***

Clean, wash, hygiene and sterile:

This group of content represent the concept of maintaining good hygiene. This was a process for the individual during interactions over time as exemplified, the education of patients and so empowering patients to self-care and be independent. Both patients and staff members were mindful of the importance of hygiene in relationship to avoiding infections particularly in patients' VAs. It was revealed by patients and staff members that maintaining good hygiene practices was a means to reduce negative outcomes for patients and therefore, decrease the risks to patients of increased morbidity and mortality.

**Patients** maintained good hygiene. This was revealed to be a strong focus during their healthcare education. Patients had reported that staff members along with the patients had endeavoured to avoid the patients' VAs developing complications through contamination and infections. As one patient reported they would 'keep their VA clean' (P9). Another patient in the same way responded this was 'Because vascular accesses needs to be kept clean and dry. To maintain our health we need to maintain the vascular access.' (P27). While another patient had similarly responded they would take 'care' (P26) of their VA and avoid risks of infection. Another patient explained they needed to maintain healthcare practices that promote 'Cleanliness' (P12) when performing their haemodialysis therapy.

A patient shared their experience of the necessity for them to take precautions in so far as their VA was concerned, by being cautious and avoiding complications for, example infection, and for this reason, they remained ever vigilant. As such, patients had reported that living with their VA had made them feel restricted in activities. As previously reported, this was demonstrated by another patient who had responded 'It makes me feel limited' (P22) in activities. Another patient responded they had felt that 'It definitely limits me' by 'always having to be cautious' (P17) protecting their VA. Patients would avoid damaging and or triggering complications to their VA wanting to avoid the risk of infections, requiring a hospital admission or 'doctor visits.' (P24). Correspondingly, another patient responded they would take measures to 'Avoid infection and clot, less drama going through all treatment to resolve complications.' (P30). As one patient responded in regards to their VA if their VA was free of complications and was viable 'I feel well.' (P20).

**Staff members** would educate patients about the care of their VA and the importance of keeping it free from complications such as infection as 'It's their lifeline.' (S10). As one staff member responded, it was important to maintain 'Proper hygiene.' (S6) when dealing with a patient's VA. One other staff member advised to avoid complications such as infections of a patient's VA care should include 'dressing, sterile technique.' (S13). A staff member explained as the 'Patients AVF is his (her) life. Need to really take good care of it.' (S14). Another staff member had responded that it was important that they 'Check access before each treatment.' (S6). Another staff member had explained 'Patients can have infection even sepsis from infected access.' (S14). While one other staff member had advised if a patient's



‘Vascular access is cared for carefully, the chance of infection is reduced and the patient’s life is not compromised’. (S13).

The concept of maintaining good hygiene was reported by patients and staff members as an important element in preventing complications such as infections. Patients were educated by staff members about maintaining good hygiene and the importance of keeping their VA clean, reducing the risks of infection and or causing complications such as loss of their VA as their “life-line”, requiring hospitalisation or the need for a new VA. Thus promoting patients to self-care, staff members were educating patients to maintain the viability and longevity of one’s VA as their life-line.

## **Person**

### ***Normal***

Physical, fit, function, normal, activities of daily living (ADLs), participating, exercise, walk, shopping, work, hobby and holiday, visiting and socializing:

This group of content embraces texts that symbolise a patient’s physical and or functional status. Participant responses had focussed on the concept of being “normal” as having an association with their ability (or barriers) to achieve their perception of normality. The individual was able (or unable) to continue their perceived normal interactions with their environment.

**Patients** had described their perception of wellbeing by referring to the term “normal”. One patient described that in relation to oneself, normal was when one felt just ‘like a normal person’ (P8). One other patient had proposed wellbeing was about being ‘normal, no pain’ (P9) living without disease and able to perform normal activities. Another patient reported that being fit and functional was an important

element in achieving normality, while another patient had proposed, 'Health is wealth' (P4). Similarly one other patient responded that to be enabled to a level of normality required 'Good health being able to shop and visit friends. Independence' (P24). One's normality was perceived as a measurement of one's health status by 'How well' you are capable to complete tasks 'in your daily life.' (P11).

One patient had responded that being normal indicated that you were capable to carry out 'lot of physical activity' and routinely complete 'exercises etc.' (P2). Exercise was reported as a compelling feature which was beneficial to achieving one's normal level of health. As an example of this perception, one patient had responded that they would 'Exercise' (P15) which they reported they had enjoyed. Patients reported they would include socialising as well as exercise as part of their normal activities of everyday living (ADLs). As an example, one patient reported when they were not attending the SHDU community, they would 'Keep physically moving' (P11) by maintaining one's social interactions, consuming a suitable dietary intake and resting. Another patient reported 'I started to walk daily from my home to the shopping centre, have a coffee with my friends' (P23) and home again. Indeed socializing visiting family and friends, attending social events, travelling and holidaying, ensuring to keep one's appointments were all seen as important elements to achieving a level of normality and or maintain both a patient's physiological and psychological wellbeing. One patient reported their perception of normality 'I think it's not all about my physical health' it is about 'mental and emotional health (P5) as well. Having a hobby and or being able to work was reported as activities which patients would do to achieve a level on normality. One patient reported that 'Being home with

their family. Enjoy being at work. Socialising with friends.’ (P1) was normal activities for them.

Patients and carers had reported the burdens one experiences as consequences of the process of ESKD, haemodialysis therapy and the patient requiring a VA as their life-line. Examples of this are the two patients who had reported they felt compromised by having a VA, mainly in their ability to engage in certain activities. By having a VA, these patients reported they felt compelled to protect their AVF (as their VA) from complications ‘It definitely limits me from participating in certain high risk activities.’ (P17). Correspondingly the other patient reported in their experience of living with an AVF, ‘It makes me feel limited in participating in certain things. Especially, physical activity.’ (P22).

**Carers** reported their own perceptions of what wellbeing represented to them. As one carer had reported normality is achieved when one ‘Is to live well eat well sleep well NOT being tired all the time having a family life, some sort of hobby.’ (CR8). Another carer had responded ‘Being able to function well and do one’s daily activities.’ (CR3). Carers shared supportive deeds they would carry out to enhance their loved one’s normality. One carer explained that ‘Making sure they are comfortable’ (CR5) enhanced one’s level of perceived normality. Other carers reported being concerned about empowering patients to be active and to live as normal a life as possible. Family and friends had reported that this had meant their carer role had developed by being attentive, helping and encouraging their loved one to undertake physical activities including ADLS. As one carer responded ‘Well yes we help them exercise. Getting changed. Going for a walk with them. Going shopping.

Help them cook.’ (CR1). Similarly another carer responded by ‘Involving them in activities (making them feel included).’ (CR5) can achieve one’s feelings of normality. While another carer shared they would support their loved one by ‘Helping them with everyday living tasks. Encouraging them to look after their health and making their health a priority.’ (CR3).

**Staff** members similarly reported that embedded within their practice, caring for patients included initiatives to encourage patients to be physically active. One staff member responded normality ‘for patients with CKD’ relates to their ability to complete ‘ADLs with no problem.’ (S8). As one patient reported the staff members would ‘Teach me to exercise’ and this made them ‘happy’ (P2). Similarly, another patient reported staff would ‘Help me perform my ADLs.’ (P4). While another patient responded the staff would ‘teach me about how and what to do. About my diet and exercise.’ (P27). A staff member responded that normality is ‘a general sense of health’ and that one is well enough to be able to ‘accomplish tasks.’ (S5).

Living with ESKD had included adhering to prescribed treatments and care activities involving both the patients and their carers. There had been reports across all participant groups that adherence to treatment regimens imposed limitations on a patient’s normality, which impacted on both their physical and mental health. Hence, this group of contexts is important as participants had viewed these issues as barriers to a patient’s ability to achieve one’s own satisfaction in reaching their goals of optimal levels of wellbeing.

Elements which are important to the patients and carers were enmeshed within this concept of being normal. By building from these positive perceptions of

normality each group i.e. patients, carers and staff members reported their own initiatives throughout the entire data set to optimise the patients' perceived level of normality. Patients, carers and staff members had reported initiatives they would take to achieve patients' level normality such as sharing information, education patients and providing supportive mechanisms for patients to achieve activities such as ADLs and exercise. Elements of normality such as exercise may have enabled patients to achieve their own perceptions of achieving their own level of perceived normality in their daily lives. The concept of being normal was reported across all groups of participants as a compelling feature exemplified by participant referring to one's ability to complete tasks involving patients ADLs which had also including a total of 14 references to the benefits of exercise to the patient.

### ***Independence and self-care***

Responsible, independence, wealth, financial status, take/self-care, monitor/assess, change/adapt, blood, eating, diet, fluid, restrictions, medications, haemo/dialysis, treatment, IBW clearance/uremic and waste:

This group of content represents the concept of promoting the patient's ability to be independent and self-caring, the concept disseminates the role of caring for the patient, by the carers and staff members within their roles as care providers. Staff members supported empowering patients and their carers in their own roles, as a collaboration of care givers, along with the patient and there carers in order to enable the patient to gain and retain an optimal level of independence through their empowerment and self-care.

**Patient** independence was reported as being gained through staff members and carers, providing enablers for patients to be independent and take on responsibilities of self-care when appropriate to their individual circumstances. One patient reported they were provided healthcare education that enabled them to take 'Personal responsibility for my own health' P24. One other patient responded within their view, monetary wealth also influenced one's ability to have an acceptable level of independence. Another patient responded retaining one's independence required 'Being healthy, Way of life, Financial Status' (P1).

Taking control, managing one's own health were factors that were perceived as important, as exemplified by reported by one patient 'good health and stay healthy by maintaining health. Need to do regular check up of our health.' (P27). Patients had reported they endeavoured to manage their own care by following prescribed healthcare treatments. One patient reported that through cautious monitoring, assessment and change adapting and adjusting their self-care based on results such as their own results of routine SHDU monthly acquired blood tests along with their fluid status 'After monthly test' (P9) the staff members discussed these results with the patient while collaborating any necessary treatment changes .

Patients described how personal achievement of independence would depend on their ability to be able to self-care. Two patients had reported they scrutinised their own blood test results along with staff, one patient reported this was to maintain their self-care by 'Monitoring electrolytes and chemicals which were stopped by kidneys' (P9) and similarly the other patient reported, they would 'Monitor care' (P13). Understanding the importance of the patients' healthcare treatments, including

attending haemodialysis therapy sessions required patients and or their carers to become empowered through education to take on responsibilities of complex care regimens. Patient education was reported to have resulted in translation of information into effective transition. Which had in fact, was reported by participants across all three groups as supportive of patients' empowerment and their ability self-care. This was exemplified by a patient who shared their values as being important for her own self-care as taking 'Personal responsibility for my own health. Stick to diet guidelines given to me by the dietician. Dialyze to the specified time set by the physician. Limit fluid as advised by staff.' (P24).

**Carers** in some self-reported cases took care of the patient's needs such as 'Give them medicine.' (CR1). Similarly, a carer reported that their role within their loved one's care was 'Making sure her health is attended to (going to doctors, being comfortable, with everything in dialysis)' (CR6). Another carer reported they endeavoured to enable their loved one to self-care by 'Encouraging them to look after their health and making their health a priority' (CR3).

**Staff** members reported they supported patients' empowerment as exemplified, by a staff member who had explained 'They provide care for the patient, furthermore attempting to gain independence, so patients can be independent with their daily living' (S5). Staff members supported patients to self-care and gain independence and as a team with the patient and their carers, they would 'Closely monitor blood results and act on them accordingly' (S8).

A patient's fluid status is important as without their retaining normal kidney function, their body frequently retained excess fluid this is due to the loss of the

patient's renal function of maintaining a healthy fluid status for the patient. Therefore, patients generally require an individualised special diet and restricted daily fluid intake, which becomes an important and restrictive element of their daily living. Subsequently staff members aimed to empower the patients through involving them in education about their treatments, including haemodialysis therapy and therefore would discuss care regimens with the patient and carers. By 'Providing dietary advice. Advise patient to monitor fluid intake.' (S6). Staff members endeavoured to maintain the patient's homeostasis through regular assessment of the patient's fluid status, assessing and setting an ideal body weight (IBW), As an element of their wellbeing a patient's IBW, was reported as one goal patients' needed to achieve as part of one's treatment regimens. Hence as part of their self-care regimen, patients were encouraged by staff members to self-monitor as well as 'adhere to their diet and fluid intake as well as their medications' (S8).

This grouping of content is relevant as a concept of patients' independence and self-caring, in so much as by being assertive, supported by carers and staff members, patients can be empowered and accept responsibility to self-care. As a concept, independence can be achieved through patients and carers having assertive communication with staff. This concept of empowering patients' independence, enabled patients to take personal responsibility for the care of one's self.

### ***Happy***

Happy, well, alive, enjoy, cheerful, humour, laugh, alright, settled, thankful, comfortable, quality of life (QOL), sleep, faith, spiritually, at peace, content, confident,



satisfied, attitude, mindset, mood, spirits, accepting, dignity, integrity, trust, privacy, respected, being heard, feeling of worth, feel special and loved:

This content includes texts that symbolise patients' happiness and comfort, as a concept which favours a more constructive or positive perception reported by respondents. The persons' characteristics such as age and or gender (Tudge et al 2009), mental or emotional resources such as past experiences and their care givers responsiveness to the individual's needs (Bronfenbrenner 1979), individual strengths such as motivation and temperament (Tudge et al 2009) can also determine one's ability to be happy. Proximal processes relate to the active individual and their environment having a bidirectional influence (Smith L 2011a). The term "happy" was the third most dominant term throughout the patients', carers' and staff members' responses, being utilised on 39 occasions, with the term "help" being used on 43 occasions.

**Patients'** their carers' and staff members' responses strongly conveyed the concept of happy, frequently referred to as positive goal, as exemplified by one patient 'Being healthy, being happy within yourself, feeling a sense of worth' (P29) were important elements of one's daily life. Patients reported they were happy with the care giving by staff members, both for themselves and their carers, within this SHDU community. One patient had recounted that this was attributed to the care they received from 'all the nurses' (P23). This suggested that the patients had gained some greater level of happiness and comfort within their healthcare through their interactions within this SHDU environment, by attending this particular SHDU community for their haemodialysis therapy and care.

Patient happiness (and level of comfort) was suggested to have been enhanced if they had an 'Acceptance of life.' (P16). As one other patient had shared 'Being kind and thoughtful' (P5) was supportive of patients' feelings of happiness. Another patient reported that they were happy with 'the treatment and care received' (P13) within this SHDU community however, they would prefer if they did not need to attend the SHDU for treatments. Patients found happiness at home and or in socialising with family and friends, working and or in maintaining a hobby. As one patient responded they would 'Hang out with family, watch TV, take care of my pigeons to keep happy.' (P8). Another patient similarly shared, they would achieve happiness at home with family 'When I'm sad my grandchildren make me very happy I play with them and they call me to come out and see them' (P14).

One patient attributed her faith in God, spirituality along with family and friends as enabling personal feelings of comfort, this patient expressing that to 'Have peace with myself, with my family and friends' further reporting that 'Being able to cope with daily life and obligations' and 'Feeling that, while I'm responsible for my daily life my faith in God had, and is still doing, helps me to cope with whatever rough patch life throws at me' (P23). Resting and maintaining adequate sleep impacted on one's happiness and level of comfort. As one other patient responded 'Sleeping well' was a valuable element of one's comfort (P11). Taking care of one-self and being well enough to be able to get around in the community to socialise with friends had made people happy. As one patient responded 'Taking care of my health' had enabled them to 'get around socially' and this had made them 'happy' (P5). Similarly one other patient responded 'Being healthy in being happy.' (P12). Another patient responded

although they had believed it would be good to be 'happy and comfortable.' their experience was 'generally old and sick all the Time' and reported 'that makes me unhappy.' (P10).

**Carers** reported the importance of their role in maintaining the patients' health, as enabling their loved one to be happy and comfortable. One carer shared as the son and a carer for his mother, his values were to enhance his mother's level of wellbeing 'After all, that is part of my duty of care, to keep her comfortable, healthy and happy. As a result, making her wellbeing improve makes me happy too.' (CR6). One other carer responded that it was important that their loved one received the best possible care when attending the SHDU community for their haemodialysis therapy and care 'so they feel happy and comfortable 'C7).

**Staff members** reported they believed in the potential benefits of the patients 'Having a positive mindset' (S3) attributing to patients' and carers' wellbeing. The staff members received praise from the patients and carers for the manner in which they were actively concerned about patient contentment, confidence and satisfaction associated with patient health care needs. Being part of the SHDU community and in the care they received from this health care service. Correspondingly, the way in which the SHDU staff members had retained a positive attitude toward the patients and carers had received praise from patients and carers. As one other staff member had proposed 'positive attitudes toward patient care, promotes positive outcomes to the patient's wellbeing.' Another staff member reported patients had indicated a positive attitude toward their need to attend the SHDU community for their haemodialysis therapy and care 'They say it's good there's dialysis' (S1).

This group of context is central to the patients' and carers' development over time. It relates a concept of caring for patients and carers, increasing their ability to feel happy and comfortable within this SHDU community's environment. Interactions between individuals –environments which are sustained over time and committed in maximising the individual's potential are proximal processes (Smith L 2011a) of one's life journey, which are the work engines of human development (Rosa & Tudge 2013). Patients, carers and staff members had described the importance of maintaining the patient's dignity, integrity and trust, as well as ensuring a patient's privacy. These important elements were reported by participants as necessary in supporting patients and carers to experience optimal levels of comfort (to be happy), enhanced by the caring attitudes of staff members and the patients' carers. This demonstrates that the element of caring, could enable the patients and their carers to feel comfortable and happy, which could have attributed to patients achieving a satisfactory level of wellbeing.

### ***Mental and emotional***

Mental, mind, psychologically, cope, stressed, anxious, emotional, feel sad, unhappy, angry, depressed, feel different, alone, unsafe, going through, concerned and need:

This grouping of content illustrates the mental and emotional health of patients. As a concept it relates to the negative effects patients and carers had reported through their and their loved ones experience during their journey in the patient's progression of living with ESKD, healthcare including treatment regimens haemodialysis therapy. Importantly, proximal processes the engines of one's development, can improve one's personal genetic potential as much as dysfunction

(Rosa & Tudge 2013). Rosa & Tudge (2013) explain that the person's environment will provide greater advantage to their development if it is both advantageous and stable, compared to a disadvantaged or disorganised environment. Hence, the concept of mental and emotional includes positive initiatives taken on by patients, carers and staff members while they endeavoured to enhance the patient's psychological (mental and emotional) health.

**Patients** reported that in their opinion, one's health represented physical, emotional and mental state as the 'whole health picture' (P17). Patients' perceptions included their own experiences that evolved around a life of managing their disease process, symptoms, treatment regimens and associated side effects in order to enable their own survival. One patient shared they relied on their psychological health 'at 78, still lets me cope' (P23). Patients reported being concerned about their health and the need to be dependent upon treatment regimens which included haemodialysis therapy and a viable VA. One other patient reported that after having experienced the pain of intervention to their AVF as their VA, they remained vigilant to avert any future complications 'I would be more alert watching it on the site the health nurse perform her/ his duty and prevent a second fistula intervention' (P9). As a staff member had explained this was important element of their wellbeing as the 'Patient's AVF is his (her) lifeline.' (S14).

Patients reported they relied on family and friends as carers and or healthcare staff members, to be supportive to enable them to cope. Certain patients through necessity had reported they relied on friends rather than family for support. As one patient explained, as they lived alone without any nearby family to support them, they

had a group of friends that 'keep in touch' (P18). Having regular contact, these friends provided the patient with both emotional and practical support within their daily living. Alternatively another patient reported they had relied on the SHDU nurses explaining 'My family' were living 'far away from me' and the nurses 'they do everything' (P32) in relation to this patient's haemodialysis therapy and care within the SHDU community.

**Carers** reported they were perceptive of their loved ones needs and shared there could also be a "domino effect" from their loved one's illness on family members 'it's hard for them to cope with the signs and also the family going through change.' (CR2). Carers reported being thoughtful of their loved one's circumstances initiating interventions to enhance the patient's psychological health. An example of this was another carer who reported as the patients' son, they would act on his initiatives to ensure his mother's psychological health 'encouraging her, reminding of the positive' (CR6). One other patient's carer had shared it was part of their role as a carer for a loved one 'giving moral support. Listening to their concerns.' (CR3). Similarly another carer had responded their role was to enhance their loved one's physical and psychological health by 'making sure all the physical, emotional, mental aspects are healthy' (CR5).

**Staff members** reported they would reassure patients, being mindful of their psychological health. One staff member reported they would 'Provide emotional support' and 'encourage patients' about the positive outcomes they could benefit from by attending the SHDU community for their 'dialysis.' (S12). Patients may feel isolated. An example of this was provided by one staff member who reported while caring for a patient who had been allocated a single room for their haemodialysis

therapy session. The effect on the patient was a feeling of isolation was reported as the patient's psychological wellbeing was compromised, this staff member had put into place steps to ensure future changes that could enhance this patient's comfort, as the 'patient stated she felt unsafe and alone. I had thoroughly listened to this patient and then organised with the NUM to have this patient in a group room for further treatments' with the patient now in the company of others, as a result of the staff member listening to her concerns, the staff member had reported 'I believe this resolved her emotional and mental anxiety' (S2). Another staff member reported it was an important element of care, that in order to support patients to achieve a satisfactory level of wellbeing, this required staff members within the SHDU community, to make certain they were 'Providing culturally sensitive care, demonstrating cultural competency.' (S5).

This grouping of content encompassed texts related to the concept of patients (and carers) psychological (mental and emotional) health. Participants had shared their perceptions of what a patient's emotional state symbolised. The concept of mental and emotional, was seen as a crucial part of patients health "picture" as reported across all three groups patients, carers and staff. Although participants had shared the negative effects of ESKD upon the patient's health, there were also responses regarding patients' resilience. This was exemplified by constructive perceptions along with participants reporting initiatives taken to improve the patients' and hence carers psychological wellbeing as both negative and positive influences on patient psychological health care outcomes, was reported as producing 'domino effect' effects on carers' health. A prime example of this was when a patient's son

reporting that in relationship to his mother's health status 'making her' level of comfort-health 'improve makes me happy too.' (CR6).

### ***Getting sick***

Disease, pain/hurt, sick/unhealthy, unwell, symptoms such as cramping, poor appetite, nausea/vomiting and breathless/SOB, dizziness, tired, old, limited, pass away/extinct/death:

This grouping of context represents the concept of "getting sick". Patients and carers had reported having endured the process of a patient's disease. Patients and carers reported their perceptions of living with a chronic disease namely ESKD, associated symptoms of the disease, endeavouring to manage complex treatment regimens, maintaining schedules including haemodialysis therapy and a VA that required care by constantly monitoring and protecting their VA while experiencing frequent painful cannulations. Therefore patients were required to cope, with often complex care regimens, effects of their disease and side effects related to treatment regimens. The patients and carers however had developed, as reported as a direct outcome of their experiences encountering these challengers through the complexity of ESKD (Arnold 2012).

**Patients** were conscious of their declining health. As one patient related 'I am getting sick and I am not able to maintain my health.' (P26). Similarly, one other patient shared that although they believed not being sick would suggest this related to 'Someone happy and comfortable' (P10). Patients shared their experiences of being sick and the routines of care that were required for one to stay alive. As an example, another patient shared that in their experience 'The fact that my veins'



(P23) were difficult to cannulate this could be a painful experience however, they had reported that pain was to be expected. If a patient's VA sustained injury and or complications, surgical intervention or a new VA may have been required. As one other patient reported they felt it was 'his/ her duty' (P9) to prevent further requirements for interventions and for this reason, they would avoid complications to their VA. Similarly, another patient reported they would monitor and take care of their VA to avoid complications such as thrombosis they would 'look at it and make sure it's working.' (P31).

**Carers** had their own perspectives of seeing their loved ones experience the burdens patients were living with in their daily lives. This included symptoms of ESKD and complexities of their treatment regimens and side effects. One carer reported if their loved one was not sick and did not have the burdens of ESKD and complex treatment regimens, this would mean for their loved one 'Being free from any debilitating symptoms like shortness of breath, tiredness, nausea or vomiting.' (CR3). Carers found it difficult to see their loved ones experiencing such burdens. As one other carer had responded 'Nobody especially her son wants to see their loved one in pain or unhealthy, which means that we would do anything in our power to be sure of it.' (CR6). As another carer explained, when a person requires haemodialysis that means their loved one is not being in good health 'they are sick and that's why they are on the machine.' (CR1).

**Staff members** responded with terms of empathy toward patients' experiences of getting sick. Staff members reported they would talk with patients and discuss measures the patient could take to control the development of symptoms as

an example, one staff member reported 'I would explain that maintaining fluid restrictions and dietary restrictions' in order 'to feel well on treatment' (S4). Similarly, another staff member responded that a patient is better prepared achievement of improving their health, if the patient has adequate 'Removal of waste product and fluid build-up in the blood. Maintaining a good diet relevant to patients with chronic kidney disease' (S6). Correspondingly, one other staff member responded, having the time to initiate early education before the patient started their first haemodialysis 'including how it works, what it helps, how to care for vascular accesses and involve them in decision making.' (S12) could help optimise patients' healthcare outcomes.

The concept of getting sick had been crucial as reported in governing patients, carers and staff perspectives. Participant responses displayed empathy for patients and carers living with ESKD, and therefore having shared values, that caring for patients was delivered with compassion. Patients, carers and staff members reported utilising initiatives that would enhance a patients' ability to achieve optimal levels of mental and physical health. Importantly, environments that are lacking challenge and are chaotic, dysfunctional and or overwhelming do not provide the person, experiences of progressive complexity for developing positive personal outcomes (Arnold 2012). As exemplified, through participant responses patients, carers and staff members reported adopting initiatives to enhance the patients' development by reducing the burden of symptoms and enabling the patients to become independent and self-caring. Staff members had responded that by supporting and reinforcing patients' empowerment in an early and timely manner, by providing education to patients (and carers) about the disease process, treatment options and management

of symptoms, diet and fluid control patients can experience independence, optimal health outcomes and wellbeing.

### ***Life-line***

Vascular/access, AVF/fistula / lifeline/veins, needle, complications, clot, aneurism, infection/ sepsis, injury, hospitalisation and intervention/surgery:

This group of contents identifies with the concept of patients' experiences living with a VA. As a patient's VA remains a permanent component of their body for their haemodialysis therapy as ongoing treatment regimens, enabling the patient's survival. In regard to level of patients' health outcomes however, the patient's VA can equally place the patient's health in a permanent state of risk of increasing morbidity or even be the cause of their mortality. Therefore, the patient's VA as their life-line has significant impacts on the patient's health outcomes and life-time.

**Patients** reported having been given explanations about their treatment and VA prior starting haemodialysis therapy. As one patient reported that before they had started their haemodialysis therapy, their options of VA had been discussed with them 'I was told about my fistula and I was happy the way things turned out.' (P20) and as long as their VA remained viable they were satisfied. One other patient had similarly responded they had eventually become used to their VA after having it for a lengthy period of time they 'Happy with it 'so it's alright.' (P14).

There were mixed levels of self-care reported by the patients themselves. One patient responded it was the nurses' role to look after the patient's VA 'I do nothing' (P32). While another patient reported that although they had been educated to self-needle their own VA for their haemodialysis therapy, they were not pressured by staff

members to continue this task 'They educated me to do self needles in insertion, but when I refuse to do it myself, they are more than happy to do it for me.' (P30).

Another patient reported how the staff members 'Help me set up' and helped with inserting the 'needles in' (P11). Another patient responded on how nurses had some difficulty needling (cannulating) the patients VA by responding this experience was 'painful at times.' (P23). This patient reported that the staff members had remained considerate of the patient's needs and displayed their regret for causing the patient discomfort by reporting 'They so understand, cheerful, with a prompt smile to help us / me. Feeling sorry for hurting me with the needles and saying 'sorry, sorry...' which helps to endure the worst part of the treatment' (P23).

**Staff members** in this SHDU community were mindful of a patient's experience, explaining to patients the importance of taking care of their VA. Staff members reported they would educate patients (and carers) about a patient's VA as 'their lifeline.' (S10). One staff member explained the care and viability of a patient's VA 'is a vital component' (S2) of a patient's care as a entirety. As VA complications can result in reduced healthcare outcomes for patients. As an example, infections, septicaemia and or thrombosis can result in the loss of the patient's VA, increased patient's risk of morbidity and or mortality.

Maintaining a process of regular monitoring of the patient's VA as one staff member reported 'Patient reassured vascular access is regularly monitored, intervention happens in a timely manner, decreases patient anxiety if problems with access.' (S4). Correspondingly another staff member responded, consistent monitoring of the patients VA promotes that the patients 'Vascular access lasts

longer' hence increasing the viability and longevity of the patients' VAs. One other staff member reported the viability of a patient's 'Vascular access is vital' for these 'patients' as the viability of a VA is crucial to the effectiveness of the patients' haemodialysis therapy and therefore the 'outcome of patient's health.' (S8). Similarly, another staff member explained a 'Good access' promotes effective haemodialysis therapy and therefore treatment regimens increase the 'benefits to their health.' (S3).

This group of content includes texts that importantly represent the concept of a patient's VA being regarded as their life-line. If a patient's VA is cared for in a timely proficient manner which includes a regimen of regular VA monitoring and surveillance, all may be favourably for patients to achieve positive healthcare outcomes. As a life-line the patient's VA is subjected to multiple and regular cannulations are generally with two needles thrice weekly, a total of at least 312 cannulations per year. This process alone increases the risks of infection, thromboses (clotting) and for this reason, patients who are living with a VA have additional risks within and to their life course.

Patients had reported the experience of being cannulated can be painful and therefore, this was reported as a distressing procedure for some patients. Importantly, patients had revealed how it may feel for them to "sit" in this position at the receiving end of these needles. Furthermore there was a constant menace to the patients, remaining at risk of experiencing dire consequences to their healthcare outcomes and result therefore to their wellbeing. Should a patient's VA sustain an injury as an example, through cannulation of the VA and as a consequence develop

complications such as infection, aneurism, thrombosis and or their VA fails (Dinwiddie et al. 2013), the patient is at risk of increased morbidity or mortality.

## **Context:**

### ***The team***

Healthcare staff, team, doctors GP, specialist, registrar, nurses, students, dietician, social worker, psychologist, manager/NUM, nurses, students, staff, resources and equipment:

This grouping of content relates to the staff members within the SHDU community along with healthcare professionals whose roles were interconnected from inside and outside this SHDU community such as doctors and allied health involved with patients care planning (pathways). As healthcare professionals involved in or with an interest in the patient's care, these individuals are included in the concept representing members of the patient's healthcare as the team. Staff members regularly reported their experiences from a view of recurrent engagement- contact with the patient, their family and or friends as carers. Within this concept of the team, patients and carers had reported ensuring their own role as being part of a patient's healthcare team.

**Patients'** roles as team members were reported as promoting patients' empowerment and as a result gain independence in self-caring. Patients reported that to achieve an enhanced wellbeing this required utilising their doctors and nurses as resources 'if I don't understand something about my treatment to ask my doctors/ nurses' (P18). One other patient responded that they valued the supportiveness of their 'family and staff' (P8). A patient's healthcare team, may include allied health

care members such as dieticians who monitor and educate patients and carers, guiding them with concerns regarding fluid and dietary intake.

As previously addressed, patients living with ESKD are compelled to live with a regimen of haemodialysis therapy and a 'Special diet. Avoid food with too much potassium. Limit Fluid intake' (P9) and a 'Low salt diet' (P17). Correspondingly, patients are also expected to negotiate 'Eating a healthy diet' (P29). One other patient explained they would 'Stick to diet guidelines given to me by the dietician.' (P24). Another patient reported there was a supportive caring approach demonstrated in the way which 'The healthcare team always helps me to maintain my health and wellbeing. They teach me how and what to do. About my diet, exercise' (P27). Available to a patient's needs within healthcare resources are equipment which specialised healthcare staff can access and utilise to enhance a patient's healthcare outcomes. For example, sonographers using ultrasound (U/S) on a patient's VA as requested by their renal physician or vascular surgeon. The patients may be requested to 'attend vascular U/S checks' (P9) as part of the process of monitoring and surveillance of their VA.

**Carers** as part of the patients' healthcare team, reported care giving for their loved one's included 'Encourage them to look after their health and making their health a priority' (CR1). Similarly carers reported they had been an advisor for their loved ones 'Giving a friend good advice on changing their diet.' (CR8). Carers had responded with how they would look after their loved one's health by ensuring their prescribed healthcare treatments were attended to. One carer had responded they would 'Give them their medicine' (CR1).

Carers reported they would accompany the patient to appointments 'Making sure their health is attended to (going to the doctors).' (CR5). Similarly, another carer had responded 'Taking a loved one to the doctor' (CR8). Carers' tasks were reported as striving to support patients to achieve positive health outcomes. Correspondingly, carers reported they would support their loved one, by initiating tasks that would avoid draining patients' health-energy reserves. As exemplified, by one carer who had reported by 'Driving my loved one to and from treatment is a task that I take on so they do not have to drive themselves as treatments do drain them physically' (CR7).

**Staff members** within the SHDU community included social workers and psychologists as part of a patient's health care team. The multi-disciplinary healthcare team had supported both the patients' and carers' sociological and psychological needs. One staff member reported some patients may need to be referred to a 'social worker, psychologist if depressed' (S4). Correspondingly another staff member reported 'I provide a psycho social assessment, which can involve providing counselling, support-emotional and practical.' (S7). Healthcare resources include the roles of staff members in both their individual and interconnecting roles. One staff member explained the patient's 'healthcare team work together' using effective communication in order to achieve 'common goals for the patient' (S6) and with the patient's family and friends as carers. Therefore, having this team approach to a patient's person-centred care has augmented providing a broader potential to enhance patients' healthcare outcomes.



As a progressive team approach, collectively with the patient and carers roles this was reported a necessity by staff members as 'It influences their physical and emotional health.' (S7). A staff member explained 'We are here to provide the best possible care to these patients.' (S9). For example, health care resources and equipment which was reported as being made available to patient requirements such as already reported, ultrasound imaging to investigate a patient's VA. Vascular surgeons along with access to theatre space and times had been available, should a patient have required vascular surgery as an example, if a patient 'experience infection, loss of access' and as a result require 'surgery to create a new one.' (S2). Another staff member had reported patients who experience haemodialysis therapy correspondingly have the need of a viable VA and therefore, they expected to have 'Confidence in the resources or equipment available to give them the best treatment.' (S11).

This group of content included texts promote the concept of "the team" attitude embedded into caring for the patient. This concept is essential to enhancing a patient's experience and health care outcomes as reported by the staff members from this SHDU community, as team members. The team draw on the various areas of health care expertise and knowledge within the group (Smith L 2011a). This is proximal processes at work, patterns of person-environment interactions (microsystems) where all levels of environmental have influence and the person's experiences takes place and where the individual's development and health care outcomes are generated in the life world of one's everyday affairs (Arnold 2012). As reported by staff members, the team of this SHDU community had a united goal to

provide care giving for patients (and carers) that promoted both the patients physical and psychological health. This team approach to patient care was to enable the patient to achieve enhanced experiences as well as health care outcomes. Secondly, incorporating both the patients' and the carers' role, as part of the team had displayed staff members respect for patient integrity and dignity thus, promoting patients' empowerment.

### ***Feeling safe***

Dialysis / centre / hospital (SHDU) and home (environment / place):

This group of content expresses the concept of feeling safe in one's environment. Patients, carers and staff members had each responded to the importance of the patients feeling safe within the environment of their health care, the SHDU community and in their home. An individual's interactions can be affected by 'relations between settings and by the larger context in which the settings are embedded' (Smith L 2011a, p. 2). This enables one's perceptions of safety through providing best practices and a safe environment, encouraged patients and carers to attend the SHDU community for the patient to participate in their haemodialysis therapy and treatment-care regimens.

**Patients** reported the importance of having the comfort and safety found at home. As demonstrated by one patient's response that 'To arrive in my home and feel safe, and protected.' (P23). Correspondingly, this concept had been symbolised by the patient who attained wellbeing by 'Being at home around family' (P1). Some patients and carers, had relayed the tasks family members would do to enhance the

patients' safety for example, 'My family members help me a lot to me my husband drops me and picks me up every day from the hospital to home.' (P26).

**Carers** reported the concept of providing a safe and loving environment at home as well as taking on tasks to maintain their loved one's safety. As an example, one carer reported 'Driving my loved one' to appointments so the patient is comfortable and safe (CR7). One other carer responded this was part of their role they would attend to daily tasks for their loved one such as 'preparing meals, cleaning the house' and ensuring their loved one was cared for and 'comfortable with everything in dialysis' (CR6). Another carer shared that the patient should feel 'comfortable' and 'feeling safe' (CR3) as this was important to both patients and their family or friends as carers.

**Staff members** at the SHDU community, reported they endeavoured to maintain a friendly and safe environment, in the way their responses had conveyed a receptive- sensitive attitude toward the patients and carers wellbeing. As one staff member described 'The team influence patient's' health and feelings of safety by making them feel relaxed in the treatment environment. Making a positive and comfortable environment encourages positive attitudes to coming to the unit to receive treatment.' (S11). Similarly, one other staff member described actions they would take to make the patient feel comfortable 'Things like getting an extra blanket or making a coffee running errands within the hospital for them' and 'Having a friendly chat goes a long way too' and also 'Asking patients how family are going and acknowledging when they are feeling down. They feel like they are 'heard' (S11). Another staff member had similarly reported, changing treatment areas for a patient,

was sometimes necessary to ensure patients felt safe and importantly ensuring treatments were safe such as 'organising with the NUM' and 'running the dialysis to assist in her physical' (S2) health outcomes while the patient attended the SHDU community.

Staff members reported that at times, the patients and or carers had required a rescheduling of haemodialysis days and or times, psycho-social support from the staff, when personal issues had developed at home. As an example one staff member had reported 'A patient on dialysis was not happy at home due to the status of his relationship with his daughter. He was from a non-English speaking background and had difficulty in communication in English. He was referred onto the social worker who with the help of a translator was able to organise respite care for the patient at a nursing home benefiting both the patient as well as the carer.' (S6).

The concept of feeling safe in one's own environments, either in their home or in the health care environment of SHDU community was an important element of for patients and carers' wellbeing. Human resilience is promoted 'by a number of environmental factors including stable housing, family connections, economic stability, school, friends and safe neighbourhood' (Boon et al. 2012, p387). Hence, feeling safe is an important element required for positive human development. Patients, carers and staff members responses displayed they were mindful of the importance of preserving a safe and friendly environment for patients and carers, both in the patient's home and within the SHDU community.

## **Time:**

### ***Time***

Period of time such as hours, months, before, after, now and then, sometimes, at times, other times, all the time, long time, regular, always, timely, prompt, quality time, my time, spending time and isolated time:

This grouping of content represents the concept of “time”. Time (chronosystem) relates to events that occur throughout an individual’s life-span within one’s environment (Boon et al. 2012). Time was reported by patients, carers and staff members to have influenced a patient’s mental and physical health and wellbeing. Such as timely education, patients and carers being included in the team at all times including “spending time” in decision making processes, being involved in healthcare treatments, carers (family and friends) chatting with staff members. These person-environment interactions are fundamental to human mental processes, which involves time in one’s proximal processes guiding an individual’s development over their life-span (Darling 2007).

**Patients** reported that over a length of time this had allowed for a level tolerance and on some occasions they had become comfortable with one’s own healthcare needs. This was exemplified by the patient who on reflection had become used to living with their VA, responding that over time they were now ‘Happy with it. I’ve had it a long time.’ (P14). One other patient reported that in relation to their VA ‘As long as it works well I feel well.’ (P20). Patients reported at times (not all the time) certain aspects of their situations bothered them as exemplified, by another patient who reported their VA had been a reminder of their ESKD and need for haemodialysis

therapy to survive, 'Some of the time I feel like because of this I am not healthy.' (P26). Similarly, another patient responded that living with a VA 'It sometimes interferes with my wellbeing.' (P8).

Patients reported they enjoyed spending time with family and friends. As one patient reported 'I enjoy my time with my family' and their 'life with work' and other social 'environments' (P13). Patients had attributed having staff members spend time with them as exemplified by having a chat or watching television, contributed to their feelings of wellbeing as 'it makes me feel like they care and belonging' (P8). Another patient reported it was important to have one's time in 'Isolation' (P17). One other patient responded the staff would spend time with them discussing their care and as a result, their wellbeing was enhanced and through one's own ability to be responsible for delivering an informed consent through staff members providing 'all the information and asked for my consent' (P22).

**Carers** reported time could be spent attending to patients' needs for example, taking positive initiatives with their loved ones, 'Going for a walks' with their loved one' and 'Spending quality time' (CR4). Staff members retained flexibility of patients' haemodialysis schedules so as they could be altered to accommodate patient and family needs 'Changing days and times to accommodate times of visiting church.' during a 'sad time' (CR6) for the patient and family, after the death of the patient's mother. Carers reported times the nurses spend caring for their loved one 'Well the nurses at haemodialysis helps my father 3 times a week on the machine, to help him get better. They are doing a beautiful job of helping him and other people like him.' (CR1).

**Staff members** responded it was comforting for the patient to spend time with them, while they were attending this SHDU community for the patient's haemodialysis therapy. As an example staying with the patient spending time 'Having a friendly chat goes a long way too.' (S11). Time was spent educating patients and carers about the patient's ESKD and treatment regimens. Staff reported the timing of a patient's and carer's education was an important factor in enhancing a patient's and their carer's translation of healthcare information into valuable knowledge. As an example, one staff member who reported timely healthcare education through being initiated prior to the patient commencing their first haemodialysis therapy, was an important element in one's psychological and physical wellbeing, empowering patients and carers to 'Provide them with sufficient education before they start' (S12).

This grouping of content relates to the important concept of "time". Time is an important factor in one's life-span while living with chronic diseases including ESKD, complex treatment regimens and relying on the viability and longevity of one's VA. As a concept, time influences the patient's ability to manage their demanding healthcare schedule, combined with patients' and carers' needs to achieve one's personal goals. Darling (2007) points out proximal processes during one's life-span i.e. over time are necessary to promote positive development of the individual. The power of proximal processes can vary depending on several factors being 'characteristics of the individual and the environment as well as the developmental outcome.' (Darling 2007, pp. 208-209).

The concept of time is crucial to the patient's care for both their physical and psychological wellbeing. Staff members reported they were respectful of patients' and

carers' needs in relation to patient's time limitations, due to their managing of restrictive complicated treatment schedules, as frequently the patient shortened life expectancy is due to their ESKD and co-morbidities. This was exemplified by staff members being flexible and rescheduling patient appointment times.

Correspondingly, the patients and staff members reported their experiences of just taking the opportunity to spend time having a "chat" with patients and carers, socialising and or addressing any concerns. Also timing or timely intervention was reported as important to empower patients and carers and reduce risks of complications having dismal effects on patients' healthcare outcomes. Staff members and carers were mindful of the patients comfort, spending time initiating timely conversations and educating patients and carers in order to effectively enhance their healthcare knowledge. This included the timely delivery of information that may have enabled the patients and carers to have the time to make informed decisions about healthcare-treatment choices, patients and carers having a voice in the planning of a patient's healthcare pathway. These are important elements of life-choices and healthcare outcomes. Time was reported by patients, carers and staff member as spent enhancing the patients' and carers' development in a positive environment, planning and putting into place optimal healthcare for the patients' life-span, over time.



## **The story continues**

In nursing, strengths based research is becoming incorporated into clinical practice however in nursing research, the use of strengths based research is still emerging. In clinical healthcare, the perspective of a strengths base care is based on key principals that every individual or family, group or community have strengths and therefore it is significant that a community is a source of rich resources. Clinical care of a patient, requires healthcare professional to focus on these strengths, rather than the patient's disease-pathology. Therefore, decisions made about health care interventions should be based on a patient's self-determination and preferences. Collaboration is the primary-essential element in the patient's and healthcare professional's relationship. Scerra (2012) points out that all individuals have the capacity to change, learn and grow. Therefore strengths paced principles can be utilised to achieve positive outcomes, empowering individuals and families in a variety of contexts.

In research, strengths based approaches aim to identify what works for participants in relationship to the research problem. This CS is intended is to explore the individuals- community's strengths in principle. Chapter six will continue the qualitative analysis of the participants' responses utilising thematic analysis, followed by a quantitative analysis which identifies the diversity of these strengths based principals.

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## **CHAPTER SIX: RESULTS OF THEMATIC ANALYSIS AND RESULTS OF MINOR QUANTITATIVE ANALYSIS**

### **Introduction**

During the third phase of thematic analysis seven key themes had been established, each of these themes represented strong patterns among participant responses.

Following the thematic analysis the results of the quantitative analysis will be presented. The seven key themes are representative of the four concepts of Bronfenbrenner's PPCT model of "process" by developing a positive perspective and empowerment, "person" binding together patient comfort and VA, "context" through a safe and friendly environment and support systems, and "time" in relationship to a patient's and or carers' QOL and wellbeing. As key themes, each possessed influential elements that were able to be drawn quite visibly from within the data and in most cases across all three groups of participant responses. I had reasoned each of these seven terms, depicted the themes appropriately, as each had retained the essence of the theme. Thus, these seven key themes would serve effectively to demonstrate the important key elements shared by participants, for the second half of the thematic analytic process. The following Table 6.1 demonstrates the seven key themes representative of the four concepts of Bronfenbrenner's PPCT model.

PPCT Model	Seven Themes
Process	Developing a positive perspective
	Necessity of Empowerment
Person	Patient comfort
	Vascular access as a life-line
Content	Safe and friendly environment
	Support systems
Time	Quality of life and wellbeing

*Table 6.1: Seven key themes: Representative of the four concepts of Bronfenbrenner's PPCT model.*

By the end of phase four, these seven key themes had maintained their utility and as to the larger extent the themes continued to succour with the research question. Drawing together the CS themes with the 4 concepts of Bronfenbrenner's PPCT model, we now explore the participants' responses, through a bioecological lens that views an individual participant as an 'active person enmeshed in an active, dynamic, social-ecological system' (Weisner 2008, p. 258). As follows, I have utilised Bronfenbrenner's PPCT model of concepts of process, person, content and time, in correspondence with these seven key themes.

## **Process: Developing positive perspectives and necessity of empowerment**

Process is the first concept of Bronfenbrenner's bioecological theory. Process takes in the "proximal processes" which involves perception, cognition, motivation and emotions (Weisner 2008). During a person's regular interactions with their immediate environment over extended periods of time, there are changes that will occur. These changes take place as the environment's influence on the individual and just as significantly there are reciprocal influences of the individual upon their immediate environment. This person-environment interaction is the concept of "process" as found to be reflected in the circumstances of the individuals within this case. The patients were required to maintain a weekly regimen of treatments, integrated in the individuals being present in this particular SHDU environment for a varied number of hours and days throughout the week. Generally as a thrice weekly routine, as confirmed by the nurse unit manager (NUM) i.e. prior to the distribution of participant questionnaires.

Regular interactions between these individuals i.e. patients, family/carers and staff members came about due to the patients ESKD with patient requiring haemodialysis therapy. The patients and their family/carers having reported frequent involvement within this SHDU community. Namely spending time together during the patient's haemodialysis therapy sessions within this SHDU community and as a result this presented recurring opportunities for these individuals to interrelate on a regular basis throughout the week as part of their 'daily life and obligations' (P23).

### ***Developing a positive perspective***

The SHDU community's participants recurrently used terms that had indicated the importance of keeping a positive perspective. An example of this attitude was demonstrated by one staff member who had reported 'By being positive and having a sense of encouragement' (S10) had helped patients to maintain a positive perspective. Correspondingly one patient had reported 'that every day I attend dialysis, all the nurses provide us all with a positive attitude to serve us.' (P23). While another staff member responded 'Making a positive and comfortable environment encourages positive attitudes' (S11). One other staff member explained that by having 'positive attitudes toward patient care promotes positive outcomes to the patient's wellbeing' (S3). Similarly one carer shared how they would find ways to elevate their loved ones comfort and perspective by 'Making sure that emotionally, she doesn't feel different or sad' the carer shared they were 'encouraging her, reminding of the positive, going on trips and holidays.' (CR6). Another carer had responded they were 'giving moral support' to their loved one 'Listening to their concerns.' (CR3). As a one staff member had explained 'By being positive and having a sense of encouragement' (S10) could better promote patients and carers to develop more positive perspectives when living with ESKD.

Patients reported they were supported by their loved one's perspective. One carer had shared methods they used endeavouring to ensure their loved one's comfort 'Provide them with intervention (or counselling) which provides emotional support, attempting to address their concerns.' additionally the carer reported they were 'Involving them in activities (making them feel included).' (CR5). One other carer

responded staff members demonstrate this by ensuring patients' and carers' inclusion, and by being mindful of the patient's experience 'Being patient with them. Paying attention to their care. Listening to them' (CR3). This carer had further responded staff members would make certain that patients and carers felt welcomed, as part of the patient's healthcare by providing information about the patient's disease process and care 'Involving their family/carers and giving them enough education.' (CR3). Correspondingly another patient responded that due to the caring of the SHDU staff members they had regained energies relaying their 'Thanks very much to all the caring and cheerful nurses' (P23). Similarly another staff member reported how the family member of a patient had expressed their gratitude for the staff members' support and caring by the 'Family (daughter) stated thank you for looking after mum' (S4) after the death of the patient's mother. Another carer had reported that 'It is important that they' their loved ones 'are well taken care of' by the SHDU staff members 'during treatment so they feel happy and comfortable.' (CR7). Therefore, the staff members' attitudes toward patient care had helped patients and carers to develop a positive perspective about their circumstances.

Communication that was effective was reported as an important element of caring. One staff member responded it was important patients 'Feel they can approach staff with any concerns or requests.' (S11). This had established that it was important for patients to feel comfortable, retaining their own place in the SHDU community. Another staff member reported they would have conversations with the patients 'to see how they were feeling' and to assess 'Were they happy coming to the unit, did they feel they could communicate their concerns to the staff looking after

them and concern was addressed or needs met.’ (S4). Similarly a patient responded the staff members would ‘Initiate a conversation with me. Spoke about my lifestyle. About my family.’ (P28). Correspondingly, patients had reported it was an important to patients ‘Being able to communicate’ (P24) through ‘Assertive communication with staff’ (P9). Another patient responded it was important to them to that having a voice in decisions made about their healthcare ‘Communicating preferences and problems’ (P17) and similarly one other patient had responded ‘communicating my concerns and problems’ (P28). These elements enhanced one’s perceptions of empowerment and hence one’s sense of wellbeing. As one staff member had explained ‘We are here to provide the best possible care for these patients. We are here to support patients, carers and educate them.’ (S9).

### ***Necessity of empowerment***

Participants across all three groups i.e. the patients, carers and staff members had reported the necessity of empowerment (referred to as empowerment from here on). Patients being empowered, to self-care and thereby achieve an optimal level of independence. As one staff member responded ‘The healthcare are very influential in a patient’s wellbeing’ as ‘Most of all, it is important to empower patients.’ (S2). Another staff member explained that the ‘team work together to achieve a common goal for the patient which is patient wellbeing through their appropriate roles and functions through effective communication’ (S6). Staff members had responded that they would endeavour to educate patients to ‘Enhance patient knowledge, involvement and encourage self-care in the satellite unit’ and therefore this could ‘Improve patient quality of life’ (S4). Education was reported as a key element to



empowering patients to make informed decisions about healthcare options. This was exemplified by one patient who responded that staff members were 'Communicating with me, kept me in the decision making process, listening to my preferences' reinforcing the patient's perceptions of one's level of empowerment, through staff members having 'Showed me how to do certain procedures and had thoroughly explained it.' (P17). Similarly another patient responded the staff members 'Help me set myself up, my fistula. Help me put my needles in.' (P11). One other staff member responded 'The healthcare team need to talk' with the 'patient to advice regarding their treatment.' (S1). Another patient by the same token had responded that 'After a monthly blood test I am informed about the results' staff members empowering the patient engaged with them sharing information and by 'highlighting the abnormalities to take care of myself or to see GP for review' or if required, the 'Healthcare nurse contacted renal specialist to change or increase medications.' (P9).

It was seen as important element of patient care, that staff members empowered patients to self-care and so achieve an optimal level of one's independence. As one staff member had explained 'Heathcare members have the ability to encourage and support HD patients, to educate them on healthcare choices which will improve their physical health, as well as refer them (if needed) to a psychologist to assist their mental health. Most of all, it is important to empower patients.' (S2). Consequently it was communicated that it was part of the staff member's role to engage in 'Education of what patient's needs to promote self-care.' (S3). Correspondingly another staff member reported that staff members 'Always encouraged patient to follow our instructions and recommendations to keep their

wellbeing (S8). As one patient had reported 'Liverpool training for dialysis has trained me well.' (P25)

One patient had responded 'The healthcare team provide an excellent care for me to maintain my wellbeing. According to my choice and comfort' (P26). One carer had responded it was important for patients that staff members 'Addressed all their concerns make them feel special and get their consent before every procedure' (CR5). Correspondingly one patient had responded 'The nurses and the doctors. Provided me with all the information and asked for my consent at all times.' (P22). Similarly another patient responded that they required staff members maintained the practice of 'Keeping me part of informed consent. Maintaining my dignity and privacy.' (P29). As another patient had explained this was 'Because I have a right to know every treatment going on me. I have a right to refuse the treatment. That's why it's better to have good knowledge of the treatment before starting' (P22) their first haemodialysis therapy treatment. Therefore patients had reported, that it was empowering for them that embedded within the staff members care giving practice, was the objective of early and consequently timely patient education to empower patients to make informed decisions regarding their healthcare.

One staff member reported it was important to empower a patient and or carers to 'Provide them with sufficient education before they start their 1<sup>st</sup> dialysis (including how it works, what it helps, how to care for vascular access and involve them in decision making).' (S12). Therefore early-timely healthcare education, for patients and their carers facilitating their ability to effectively translate healthcare information into valuable knowledge could more effectively empower patients and

carers to make informed choices regarding the patients' healthcare choices. Similarly one other staff member responded 'We are here to support patients and carers and educate them.' (S9). Correspondingly another staff member had responded 'good education for the patient' led to enabling a patient, carer and staff members to 'Provide proper treatment' (S14) thus enhancing the patient's and carers' goals of wellbeing. One other staff member had cautioned it was imperative that the 'Healthcare team should have sufficient knowledge and education to care for patient.' (S13).

The patient's everyday living was affected by the burdens of their ESKD and treatment regimens. Wellbeing for this group of patients, as reported by one staff member did not fit the general consensus of satisfactory as 'Wellbeing is a general sense of health, so in every aspect you're healthy. It means that you are fit enough to successfully accomplish tasks.' (S5). Patients frequently faced barriers to achieving their ADLs. For this reason, it was important that patients were empowered to be able to manage their ADLs. As another staff member responded 'Wellbeing for patients with CKD means that they are able to meet their ADLs with no problem.' (S8). As such, one patient had reported staff members would 'Help me perform my ADLs.' (P4).

Staff members had responded that their aim had been to enhance patients to empower them through 'sharing of information and carrying out plans, assessing the outcome and making adjustments based on the outcomes' (S6). As one patient had responded it was important that they were empowered to self-care such as being empowered through education and the support of staff members and carers to be

enabled and by 'Taking care of my health by medication makes me able to get around socially which makes me happy.' (P5). Educating patients and their carers about the patient's health along with their healthcare required sharing of information concerning individualised patient's treatments, diets and fluid restrictions.

Haemodialysis therapy to a small degree, replaces one's kidney functions such as 'water and waste removed from blood to prevent symptoms' (S13). Patients are required to follow dietary and fluid intake restrictions. In that order, another patient reported the staff members would 'teach me about how and what to do. About my diet and exercise.' (P27). Maintaining one's health requires patients to 'adhere to their diet relevant to patient' (S5) and their individualised healthcare treatments. Another staff member had explained that by patient's being empowered to self-care 'maintaining fluid restrictions and dietary restrictions' the patient 'can decrease problems that they may get on haemodialysis like dizzy, breathless, cramping, short of breath etc.' and if the patient's 'blood results are in good control they can decrease problems with bone disease, anaemia, their appetite' and therefore the patient's 'health improves maintaining them to feel well on treatment etc.' (S4).

Enabling a patient's empowerment to self-care, required staff members to provide information that could improve a patient's healthcare quality of life and wellbeing. As one staff member explained, this is why it is 'important to empower patients.' (S6). One patient had responded that as a result of the staff members involving them in their healthcare and educating them, they were enabled having 'Achieved training for my dialysis' they had been empowered to master tasks of self-care such as 'doing my dialysis myself.' (P25). Supporting the patients'

empowerment, as another staff member reported, acknowledges the patient's rights, is an important element of care giving. Ultimately enabled patients to be empowered to self-care, requires effective communication ensuring patients' and carers 'feel like they are being heard as a person not just as a patient/client.' (S11).

### **Person: Patient comfort and vascular access as a life-line**

Person is signified by Bronfenbrenner's PCCT model to include genetic, physical, psychological and behavioural characteristics (Smith L 2011a). Saxena and Adamsons (2013) explains the concept of "person" in this model, is viewed as three integrated components:

- Demand: The person's individual characteristics, such as their physical appearance e.g. hair colour or skin colour, their age and gender. Individualities who promote an immediate difference from another person.
- Resource: A person's characteristics that are less immediate of another individual's recognition e.g. their personal experiences, abilities, intellects, as well as resources they have access to both social and material.
- Force: Concerns a person's characteristics by their individuality according to motivation, persistence and temperament.

### ***Patient comfort***

Patient comfort was a frequent theme throughout responses across all three groups of participants. As one carer had responded their role included ensuring their loved one was 'comfortable with everything in the dialysis.' (CR6). One patient's response was their understanding of the term wellbeing would be 'Someone happy and comfortable. But in my case I am generally old and sick all the Time that makes me

unhappy.’ (P10). Staff members had explained that for patients who experienced the burdens of contributing negative factors of living with ESKD, this can lead to the patient’s sense of wellbeing being generally compromised. Patients had to manage a ‘Condition where the person is not physically healthy and emotionally healthy’ and therefore correspondingly they may not be ‘psychologically healthy.’ (S12).

Wellbeing is ‘Very important’ (S14). One patient reported having an ‘Acceptance of life.’ (P16) would enable one’s comfort and one’s wellbeing. As one staff member explained wellbeing was about being ‘Mentally content with how their health is being managed and maintained’ (S11). Another patient responded the term wellbeing, relates to ‘The whole health picture, physically, mentally and emotionally’ (P17). Correspondingly another staff member responded ‘Wellbeing is a sense of either balance or satisfaction in the physical, emotional, spiritual and mental aspects of a person’s life.’ (S1) hence, enabling an individual’s comfort.

The manner, in which care was delivered enabling the patients’ comfort, was reported by one carer to include elements of ‘Respecting their beliefs, values and culture. Maintaining their dignity’ (CR5). Another carer saw maintaining their loved one’s comfort as part of their own role as a care giver by sharing they endeavoured ‘Making sure they’ their loved one ‘are comfortable (i.e. showering them, preparing meals, cleaning the house, purchasing a bed similar to the hospital beds where she can sit up and adjust her position easily.’ (CR6). As one staff member explained patients can experience a restricted lifestyle and for patients and carers this can be ‘pretty hard you cannot just go travelling (S1). As patients have responsibilities as much of the patient’s time is spent ‘committed with your treatment’ and arrangement

need to be made such as 'make bookings' (S1) to have alternative locations for the patient's haemodialysis therapy times covered by healthcare facilities at their holiday destination and only then if a one becomes available.

Maintaining flexibility in the routines of a patient's haemodialysis therapy sessions was seen as an important element of the patient's care and therefore, accommodating for patients and family/carers to continue a more normal family and social life. As exemplified by one carer who had reported that after the death of a patient's mother the staff had accommodated for the patient's and her family's needs 'They did this by changing dialysis days and times to accommodate' for their needs, further reporting that staff members had 'sent a card to mum and family to comfort us in this sad time.' (CR6). Similarly a patient had reported after a friend had passed away 'Staff sat with me and gave me emotional support plus offered to change dialysis appointments to suit my needs.' (P24). Correspondingly a staff member had responded 'Flexibility with sessions' of the patients schedule of haemodialysis therapies was necessary 'in order' for patient and carers 'to attend important events to enable patients to maintain a sense of having a social interaction' (S3) was important for patients and carers, to continue some optimal level of normality in one's everyday living.

Retaining a beneficial level of one's normality was reported as enhancing one's wellbeing. As one patient had shared to feel comfortable requires a level of wellbeing where 'All the body is normal' (P9) and correspondingly another patient responded the term wellbeing correlated with one's ability to 'Feel like a normal person.' (P8). Patients and staff members had reported wellbeing was a

measurement of one's personal comfort and ability to complete tasks. One staff member explained wellbeing was 'Feeling better about your-self and able to do' one's ADLs 'without restriction of the underlying disease.' (S10).

Exercising was seen as enhancing patient comfort and being a part of one's normal daily activities. As one patient responded wellbeing was signified by 'How well you are to carry out physical activities in your daily life.' (P11) and correspondingly another patient responded 'That you can do a lot of physical activity, exercises etc.' (P2). Patients had reported finding comfort and enjoyment in 'Exercise, walking and physical activity' (P2) and correspondingly another patient had responded they would 'Exercise and be happy' (P15). Similarly another patient had responded they would 'Walk on treadmill. Keep physically moving, meet people. Eat well. Sleep well.' (P11). Exercise was reportedly as a strong element to promoting patient normality and hence QOL and wellbeing. Another patient had shared their own experiences by reporting 'I started to walk daily from my home to the shopping centre, have a coffee with my friends and back home with a newspaper under my arm, admiring the gardens, I pass in front of me, and Feeling alive' (P23).

### ***Vascular access as a life-line***

A patient's VA as a life-line (referred to as VA from here on) was reported by patients and staff members to be a vital component of the patient's care and wellbeing. As one staff member explained 'because with a poor vascular assess the patient can experience infection, loss of access, surgery to create a new one, withdrawal from treatment, a hospital stay, and even death. All these complications can have physical, emotional and social effects on an individual's life.' (S2). For these reasons, staff



members roles had included educating patients about their vascular assess in 'Techniques of care and its importance to make it clean and dry.' (P26). Another patient responded it was important to maintain one's 'Cleanliness when performing dialysis.' (P12). By maintaining a 'Sterile field' (P15) during procedures such as cannulation of a patient's VA as well as attending to one's personal 'Hygiene care' and correspondingly to 'Monitor care.' (P13) of one's VA. Similarly another patient had responded that they had taken care of the VA to 'prevent infection in the fistula site' continuing to explain that they would 'Always wash and keep clean and free from injury.' (P9). As another patient explained they would take care of their VA 'To avoid hospital admission. Avoid infections.' and as such, they would require 'Less doctor visits.' (P24).

Patients had been asked if the care of their VA contributed to their wellbeing. One patient reported 'Not at all.' Similarly another patient had responded 'None' (16). While another patient had responded that their VA 'doesn't contribute.' (P29) to their wellbeing and another patient had responded that 'The nurses care for my vascular access.' and as such 'I do nothing.' (P32). One patient had responded to this same question by 'Some of the time.' and that by having a VA 'I feel like because of this I am not healthy' (P26) as their VA was a constant reminder of their poor health. One other patient responded 'I would be happy if I didn't have to come to the dialysis centre.' (P13).

The constant need to protect their VA from injury or complications, as one patient had responded 'sometimes interferes with my wellbeing.' and had further explained that 'The fistula sometimes stops me from doing things I'd usually do.' (P8).

Patients had reported having a VA does not lead to wellbeing as their haemodialysis therapy included cannulation of the VA and therefore, these treatments were neither 'comfortable' nor 'pain free.' (CR3). Correspondingly another patient had explained it can be uncomfortable for patients who experience during the routine of haemodialysis therapies their 'inserting the needles very hard and painful at times. I wouldn't come to dialysis thinking that it was a 'free pain zone.' (P23). Although this patient had responded that the staff members had demonstrated that they had remained considerate of the patient's needs and had voiced that they were regretful for causing patients these episodes of discomfort 'They are so understanding, cheerful, with a prompt smile to help us / me' the patient responded that staff members had displayed they were 'Feeling sorry for hurting me with the needles and saying 'sorry, sorry...' which helps to endure the worst part of the treatment.' (P23).

Patients reported that their VA care had to some lesser or greater extent, contributed to their wellbeing. One patient had responded 'Somewhat yes' (P10) while another patient had responded that this was true 'Some' (P21) of the time. Another patient had reported 'I feel better' (P11) and correspondingly 'It has helped me regain energies I had lost' and had further reported that their VA had 'enabled me' (P23) to complete daily activities. Similarly another patient responded their VA had enabled them to feel well enough to continue to 'Exercise' and maintain walking and general daily 'physical activity.' (P2). One other patient had responded that 'It is very important to make sure I exercise and look after my fistula as I have been told to do so.' (P18). As another patient had responded in regards to living a life with a VA and having to take care of it 'As long as it works well feel well.' (P20).

One patient responded that having a VA had improved their 'Health' although 'not wellbeing.' (P4). Patients had reported that by having to protect their VA as their life-line from complications 'It makes me feel limited from participating in certain things; Especially, physical activities.' (P22). Another patient had similarly responded 'It definitely limits me from participating in certain high risky activities. The care for it is factor. Furthermore, keeping it clean from infection, always having to be cautious' (P17). One other patient had in the same way reported that by having a VA, it had made them feel compromised by making it 'Hard for ADLs activities.' (P12). Another patient had reported their experience, having already endured an incident where complications had led to the failure of their primary VA they would closely monitored the nurses practices during cannulation procedures and to 'Avoid clotting, I keep on caring for it since I got a clot. After that incident I always have a good look at it and make sure it's working.' (P31). While one other patient had explained that it was much less an issue to protect their VA from complications to 'Avoid infection and clot, less drama going through all treatment to resolve complications to their vascular access.' (P30).

A staff member responded that a patient's VA 'is his (her) lifeline.' (S14). Correspondingly another staff member had explained the patient's 'Vascular access is vital in the wellbeing of patients because this reflected how good HD treatment is being effective on the outcome of patient health.' (S8). In the same way another staff member had further explained that a 'Good access equals good treatment equals patient happy with treatment and the tangible benefits to their health.' (S3). As one patient responded their 'Vascular care needs to be done properly and put clean and

dry. To maintain our health we need to maintain the vascular access.’ (P27). For this reason, ensuring the safe management and care of a patient’s VA by supporting patients’ timely and early education and commencing patients’ haemodialysis therapy with a mature VA, following appropriate cannulation techniques, routine protection, monitoring and surveillance procedures which aim to retain the viability and longevity of a patient’s VA. As one staff member explained the patient’s ‘Vascular access lasts longer. Lower rates of complications such as lower risk of infection. Lower tendency to clot.’ (S6). As one other patient responded their ‘Vascular access has been well looked after.’ following an early start of education and planning of their VA had enabled this patient by ‘Giving a good entry to dialysis.’ (P25).

### **Context: Safe and friendly environment and support systems**

As Bronfenbrenner’s latest framework, the four concepts of his PCCT model, had reemphasized the developmental transformation of the person in context over time (Tudge et al. 2009; Weisner 2008). Bronfenbrenner theory of bioecology concerns the system ‘person-environment interaction in each particular context’ (Weisner 2008, p. 261) in which relationships develop. Bronfenbrenner’s biological theory is about understanding what makes humans being human (Bronfenbrenner 2005).

Consequently, it is essential that we understand the biological resources individuals within the SHDU community had developed and on which patients and their carers might have relied upon. For example patients in ESKD are generally required to walk the tight rope of adherence to their medical regimen-independence (Curtin et al. 1997). The theme of safe and friendly environment and supportive systems communicated these elements had helped to enable the patient to enhance one’s

sense of empowerment including their ability to self-care and retain some greater level of independence. The utilisation of this PPCT model, had allowed a more effective process of examining the entire data set, through the utility of themes to understand the “accommodation” or fit between the person and their environment (Weisner 2008). This CS was then able to represent the person in the context of this SHDU community.

### ***Safe and friendly environment***

The SHDU community was commonly reported among participant responses, as being a safe and friendly environment and as such was seen as enabling and supporting patients in their autonomy and independence in everyday living. One staff member reported that ‘The team influence patient’s wellbeing by making them feel relaxed in the treatment environment’ (S11). One other staff member explained ‘The healthcare team work together to achieve a common goal’ of patient ‘wellbeing’ (S6). As one patient had responded ‘Everything about the care and the treatment that I receive.’ (P13) had concerned their wellbeing. As another staff member proposed the healthcare environment ‘influences their’ the patients ‘physical and emotional health?’ (S7).

Patients were encouraged to socialise in their larger community as well as while attending the SHDU community. As one patient had responded in regards to the attitudes of the SHDU staff members ‘They are understanding, cheerful, and with a prompt smile.’ (P23). Similarly another patient had responded ‘Seeing everybody here (nurses, students other clients) are my family and friends.’ (P14). One carer had explained the staff members ‘always care very much for them in dialysis and are nice

and friendly. This uplifts and encourages them.’(CR6). One other patient had responded that they were ‘Always happy and everyone here’ at the SHDU ‘helps me stay happy.’ (P14). Similarly another patient reported ‘Sometimes the nurse spends ten minutes with me to watch TV’ further reporting ‘it makes me feel like they care and belonging because we laugh together. Other times they also make conversation with me and jokes.’ (P8). One staff member explained ‘Wellbeing is how you feel about yourself. It is a combination of emotional, physical, mental and social factors.’ (S9) and therefore it is important, that the environments that you are part of are both safe and friendly. As one patient had reported, in relation to the practices involving the care giving by staff members ‘Their wonderful sense of humour and just being there, always alert to any of us needing their help.’ (P23).

Carers had reported they would check and confirm suitable care was being provided for their loved ones. As one carer reported it was part of a carers role, that they check their loved ones needs were being met at the SHDU community, by personally ‘Making sure her health was attended to’ (CR6). One patient had reported that after having experienced complications to their VA ‘I would remain alert watching it on the site the health nurse perform his/her duty’ (P9). A staff member had reported that ‘The team influence the patient’s wellbeing’ explaining that ‘by making them feel relaxed in the treatment environment. Making positive and comfortable environment encourages positive attitudes towards coming to the unit to receive treatment.’ (S11).

One staff member responded that it was important for patients ‘Being able to come in and out’ of the SHDU ‘with confidence in the staff and resources available.’ (S3). As one patient had reported ‘Most of the staff are friendly and I am happy with

them.’ (P10). Similarly another patient had responded, that it was important that the SHDU staff members had followed ‘Good and safe practice in healthcare.’ (P30). One staff member had explained it was important that the patient ‘Feels comfortable in’ their ‘environment’ (S11).

Patients and carers had likewise reported that the patients while at home and in their immediate community gained from enjoying a safe and friendly environment, as one patient had shared ‘To arrive home and feel safe, protected.’ (P23) was an important enabler to their wellbeing. Enjoying family and friends in a safe and supportive environment as another patient responded ‘Being at home around family. Enjoy being at work. Socializing with people.’ (P1) supported their perception of enhanced one’s wellbeing. Patients, carers and staff members reported that there was a supportive element which had nurtured personal comfort and development within this SHDU community. As one patient responded ‘Nurses, doctors were supportive’ which had ‘Assisted with level of wellbeing.’ (P1). Similarly another patient responded that the staff members were caring by ‘Being kind and thoughtful helps me feel happy’ (P5) and another patient had responded the ‘Healthcare team helped me a lot. Provide support for me.’ (P21).

### ***Support systems***

Patients had shared having support systems available such as a loving family and friends was advantage, as well as being part of a positive environment within this particular SHDU community. One patient had shared ‘My family are so supportive specially my daughter and my carer (daughter in law).’ (P10). A patient’s relationships with family and friends had been communicated through participant responses as an

important resource for enhancing their wellbeing. As exemplified by one patient, who had shared 'To feel loved by my children and their families. To have friends who are with me, celebrating or comforting me when sorrow clouded my life' continuing to explain these relationships over time had enabled this patient cope and be happy 'Above all, for my mental strength which at 78, still lets me cope with old age infirmity, and yet, feel young at heart, and, able to enjoy good' (P23). Another patient had responded similarly in that their family 'Did simple tasks to check on me or supporting me with my decisions.' (P17).

One carer responded 'I know the person and I would know what they are going through' further responding 'it's hard for them to cope with the signs and also the family going through change.' (CR3). Although some patients had responded that instead of family, they had relied upon support systems which had included friends rather than family members. This concept was exemplified by one patient who had responded 'As I live alone and family live interstate I have a group of friends that keep in touch at least 3-4 times a week' further adding this was 'to make sure I am alright and if I need anything.' (P18). One staff member had responded that they would 'Provide emotional support and encourage patient to come for their dialysis.' (S12). Again some patients had no family close at hand and reported they had relied on the SHDU staff members as their main support system 'My family members (4 sons) live far away from me' and as such the SHDU staff members 'do everything for me' (P23). While other patients had responded they attributed their 'Good wellbeing' on the 'Support of family and staff'. (P8).



## **Time: QOL and Wellbeing**

Bronfenbrenner's final concept of time is a longitudinal understanding of the patient and carers wellbeing as they experience a continuum of changes. Humans adapt and develop as individuals through their regular interactions over extended periods of time (Rosa & Tudge 2013; Tudge et al. 2009). As such, one's QOL and wellbeing cannot be fully understood as arising from a single point in time. Patients and carers QOL and wellbeing changes and evolves as they experience the ups and downs of living with ESKD and related incumbencies. This includes the patient's healthcare regimens necessitated by the patient's healthcare needs living with ESKD and a VA to sustain and optimally gain an optimal level of QOL and wellbeing.

### ***QOL and wellbeing***

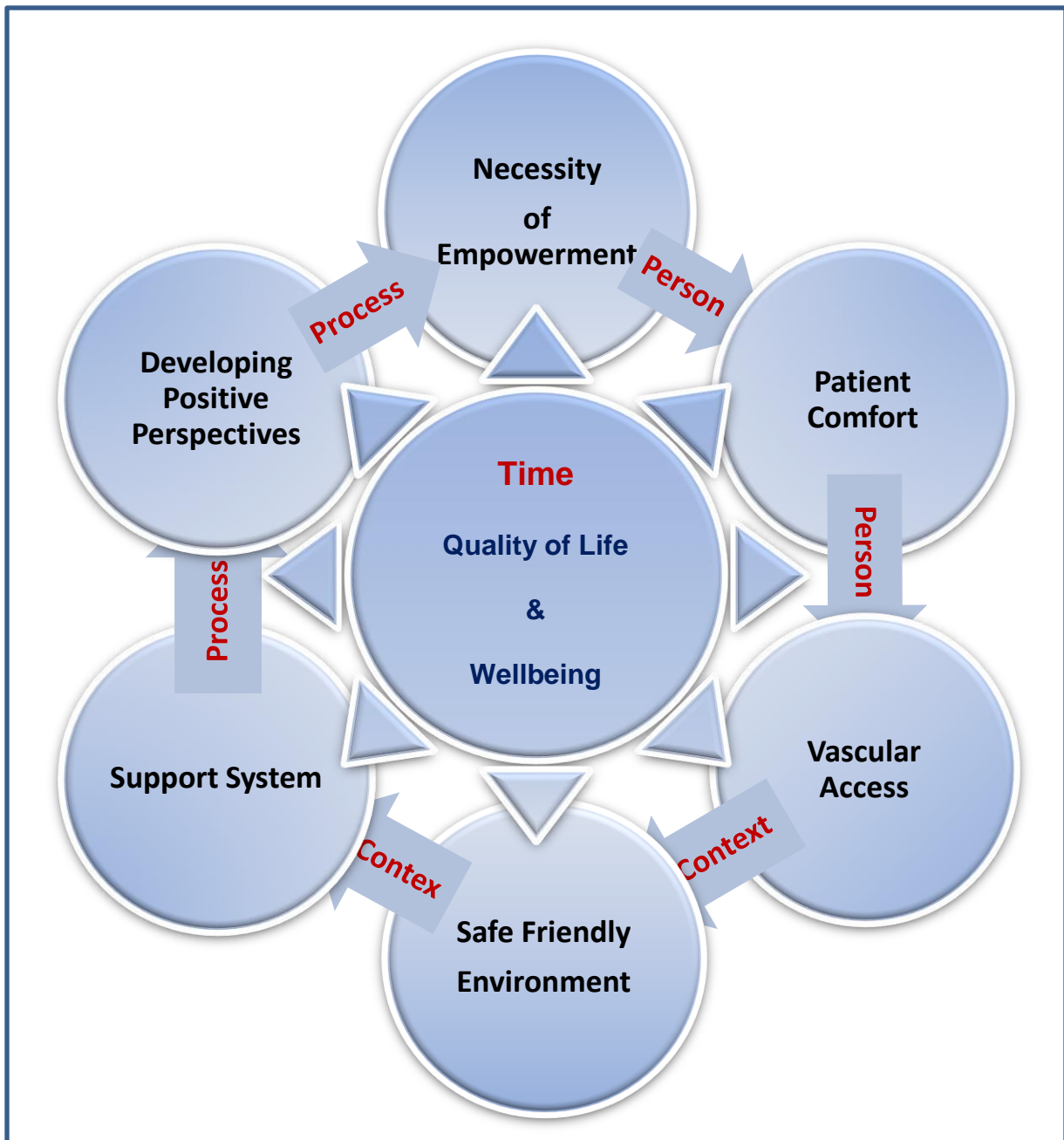
Our first research question had asked of participants "What does the term wellbeing mean to you". One patient's response had been wellbeing is achieved when 'All the body is normal' you live without 'pain' or 'disease and that you are able to 'work' and complete daily obligations and activities, and that your 'mind is normal' (P9). Similarly, another patient had responded 'Wellbeing means the whole picture, physically, mentally and emotionally. Wellbeing is being happy within yourself and happy with your surroundings.' (P17). While another patient had answered 'If someone asked about my wellbeing I think it's not all about my physical health but also my mental and emotional health (P5). One other patient responded wellbeing was about 'Good health being able to shop and visit friends. Independence. Able to do own housework' and importantly 'Being able to communicate.' (P24). One carer had shared 'To me,

wellbeing means being comfortable, pain free in good mood and spirits and feeling safe.’ (CR3).

Time had allowed for some level of patient comfort. As one staff member had reported after talking with patients it ‘looks like they are able to accept their situation. They even say it’s good there’s dialysis.’ (S1). A team approach to patient care was practiced within the SHDU community. Patients were offered referral to auxiliary healthcare members to ‘Improve patient quality of life e.g. referral to specialist, social worker, dietician. etc.’ (S4). One patient had reported ‘Wellbeing means looking after myself and others’ (P25). Another patient had responded ‘Health is everything for me. I need to be stay healthy and maintain my health. Do regular check-ups take medication on time. Do dressings. Regular exercise.’ (P27). One patient had reported that the staff members ‘Teach me to exercise, that makes me happy to achieve my wellbeing’ (P2). Correspondingly another patient had responded that they had accepted personal responsibility and for this reason, had set themselves personal tasks to ‘Ensure that I stay well. Minimize potential problems.’ (P31). Similarly one other patient responded they had taken ‘Personal responsibility for my own health.’ endeavouring to ‘Stick to diet guidelines given to me by the dietician. Dialyze to the specified time set by the renal physician’ and would ‘Limit fluid as advised by staff. Exercise as physically possible’ further reporting that they would take precautions to protect their fistula, such as ‘not lift heavy objects with my fistula arm.’ (P24).

Patients and carers had reported that time was seen as “spending” time to promote one’s wellbeing. As one carer responded they would spend time ‘Going for walks with him every Sunday. Spending quality time.’ (CR4). Correspondingly another

patient had responded they had enjoyed 'Spending quality Time with my kids, visiting them.' (P10). While one other patient shared 'I enjoy my time with my family members enjoying life with work and other environments.' (P13). While another patient reported they had enjoyed their times of being alone as 'Isolation time.' (P17). Time was reported as providing an eventual acceptance of one's situation. As one patient had reported, living with ESKD and a VA and therefore changes to one's life and body, over a lengthy period of time they had become 'Happy with it, I've had it a long time so it's alright.' (P14). These themes are diagrammatically represented in Diagram 6.1 'The bioecology of the satellite haemodialysis unit as a community'.



*Diagram 6.1: The bioecology of the satellite haemodialysis unit as a community.*

## Results of Quantitative data analysis

This CS utilised a mixed methods research design classified as an embedded correlational model with a minor focus on quantitative data exploring correlations

between variables (see Diagram 4.1 'Mixed methods research design'). As an embedded correlational model of research the appropriate quantitative analysis for this study was correlation analysis of the variables included in the instrumentation.

The variables available from the instrumentation were:

- Physical Component Scale (PCS) and the Mental Component Scale (MCS) from the SF-36v2®,
  - family strengths scale (FSS),
  - patient empowerment scale (PES), and
  - family attributes satisfaction scale—Health Care Professionals (FSAS-HCP),
- (See Quantitative Data Analysis Chapter 4).

31 patients attending the SHDU community returned the quantitative components of the questionnaires. Of these 31 participating patients:

- 29 patients completed questions within the SF-36v2®, family strengths scale (FSS), patient empowerment scale (PES) and family attributes satisfaction scale—Health Care Professionals (FSAS-HCP);
- 2 patients completed the SF-36v2® only of the case study questionnaire.

For correlation analysis this left a maximum participant population of 29 ( $n=29$ ).

Where data was missing, the guidelines of SF-36v2® were followed. There was a total of 15 items not answered and all the missing data were treated as per the SF-36v2® guidelines (Maruish 2011). Due to the construction of the SF-36v2® it was not possible to correct for missing items for one participant's answers related to the Physical Component Scale (PCS) resulting in  $n=28$  for the analysis involving the

PCS, instead of  $n=29$  as for the analysis involving the Mental Component Scale (MCS).

### **Exploring patient wellbeing: The relative influence of factors**

The collected empirical data allowed for relationships between covariates associated with patient wellbeing to be explored. Field (2005, p. 123) advocates the use of 1 tailed test when directional predictability is theoretically supported by the descriptive theory. The descriptive theory of this case study has informed the decision to use 1 tailed test of significance. Caution in interpretation of causality from correlation coefficient is required (Field 2005, p. 127). The effect size however, of the strength of the relationship between two or more variables can be estimated from the correlation coefficient (Field 2005, p. 32). Effect sizes have practical importance in that they are resistant to the influence of participant sample sizes and therefore utilised to provide an 'accurate measure of the magnitude of effect between variables' (Kobayashi et al. 2014, p. 9). Interpretation of correlation coefficient of .5, .3, and .1 can be regarded as large (or clear), moderate and small respectively (Meyers et al. 2006, p. 115).

When data can be ordered in a meaningful way, it is ordinal and therefore non-parametric. Non-parametric test for correlation include Spearman rank order correlation or Kendall rank coefficient of concordance (Field 2005, p. 129). Salkind (2010) recommends Spearman rank order correlation when data sets contain a large range of values and reduced frequency of tied ranks. Kendall rank coefficient of concordance is the recommended test when there is a small data set and many scores have the same rank (or value) (Field 2005, p. 131). Kendall rank coefficient

of concordance is often used with data sets involving  $n < 20$  (Legendre 2010).

Although the data set in this study was  $n = 28$ , it remains a small data set in relation to the number of variables explored. Initially the quantitative data was checked for ranking, as ranking of scores may have an influence on correlational analysis (Salkind 2010). Examination of the variables revealed three of the five variable scores had increased frequency of tied ranks. The variable FSAS-HCP and PES revealed 75% of the scores and for FSS 40% of the scores tied rank with at least one other score. PCS or MCS revealed no tied ranked scores, as the SF-36v2® computes outcomes to two decimal places. Ranking to the scores of the entire data set was 38%. The effect of tied ranking on Spearman rank coefficient is often only significant when 25% or more of the entire data set are ranked (Salkind 2010). For the data set it was determined that Kendall rank coefficient of concordance provided the most reliable and conservative estimate of association between variables.

Utilising SPSSv23 the results on Kendall rank correlation,  $\tau$ , (1-tailed) analysis was undertaken and the results of the non-parametric correlations are presented in Appendix 14. 'Non-parametric correlations'. From the correlations table the following significant associations of interest were identified:

1. Regarding the patient empowerment scale, there was a clear association between family strength attributes scale-healthcare professionals and the patient empowerment scale ( $\tau = .292$ ,  $p$  (1-tailed)  $= .018$   $n=29$ ).
2. Regarding the PCS of the SF-36v2®, there was a clear association between the patient empowerment scale and the PCS ( $\tau = .336$ ,  $p$  (1-tailed)  $= .008$ ).

$n=28$ ).

3. Regarding the MCS of the SF-36v2®, there was a clear association between family strength attributes scale-healthcare professionals and the MCS ( $\tau = .338$ ,  $p$  (1-tailed)  $= .006$   $n=29$ ) and there was a clear association between family satisfaction scale (FSS) and the MCS ( $\tau = .422$ ,  $p$  (1-tailed)  $= .001$   $n=29$ ).

The strength of the relationship identified through  $\tau$  indicates a medium effect on the outcome indicators of PCS and MCS. PCS was demonstrated to be related to PES and MCS was demonstrated to be related to Family Satisfaction Scale (FSS) and Family Strength Attributes Scale (FSAS). This suggested that the patient's satisfaction with the display of family strengths from both their own family and from the healthcare professionals of the SHDU had a medium effect on the mental wellbeing of the participants with the effect greatest associated with satisfaction of own family's strengths. The  $\tau$  also demonstrated that the patient's empowerment had a medium effect on the mental wellbeing of the participants although this effect is not as strong. These results demonstrate an association between the patient's mental wellbeing (MCS) and the ecology of both their family and the SHDU (see Appendix14. 'Non-parametric Correlations').



## **CHAPTER SEVEN: DISCUSSION**

### **Introduction**

This chapter will follow the pattern of reporting findings related to the quintain advocated by Stake (2005). Stake (2005) argues it is important for a CS report to 'show how the quintain is newly conceptualised as a result of the study' (p. 81). This chapter will discuss the research findings with the aim of conceptualising the results in a new synthesis of understanding the phenomena of care of a patient's VA for haemodialysis articulated through six statements. The PPCT model of the bioecological theory of human development will be used as a framework to discuss the results of the CS and reconceptualise the quintain.

### **Ecology of healthcare: Developing a positive perspective**

#### ***Statement one:***

Promoting bidirectional proximal processes (relationships in their ecology within the SHDU community) between the patients, family/carers and staff members may effectively support patient wellbeing.

There is little known about the impact of healthcare's organisational culture on patients' healthcare outcomes, in regard to a patient's and or their family's/carers' lives during and after the patient is discharged from treatment/hospital and returns home (Alharbi et al. 2014). Since the 1980's, organisational culture has concentrated on measuring the normative glue that holds together individuals within an organisation. Quinn and Rohrbaugh (1983) divided organisational culture into two opposing complex differing dimensions. Firstly, the dimension of human relationships

and open systems, that value flexibility, cohesion and trust. Secondly, there is an opposing dimension composed of internal processes and rational goal which place value on routines, control and stability. Environments displaying a culture that include flexibility, cohesion and trust will more readily embrace change. While cultures that include routine, control and stability frequently resist change, have a superior capacity to maintain the effects of such changes, once they have been implemented (Alharbi et al. 2014).

People attending a SHDU for their haemodialysis therapy and their family/carers generally follow a stable routine of treatments, which include the patients attending the SHDU as a community thrice weekly for their therapy (see Appendix 2. 'Understanding the journey travelled by patients and carers living with end stage kidney disease and haemodialysis.')

The intensity of one's individual connection with other individuals within the environment of this SHDU community had reportedly developed along with their experiences of living with ESKD. Interactions were shared both within the SHDU environment, with family members and friends within in their larger community. Therefore it had been conveyed through participant responses, that there had been reciprocal influences of the environment on the person along with reciprocal influenced of the person on their environments i.e. at home, with family and friends and or within the SDHU community.

Patient, carer and staff member responses had recurrently demonstrated a kind nature within roles of care giving and receiving. As shared though participant responses this element, was regarded as promoting patient and family/carers to

retain a positive perspective when faced with living with ESKD. Reportedly this element was embedded into caring, which had asserted essential influences upon the patient's and family's/carers' daily lives. In the same respect, the SHDU staff members were reportedly perceived by family/carers as being instrumental to their loved ones development of positive perspectives toward their own personal circumstances.

The supportive culture of staff members, in being concerned with patients' and family's/carers' wellbeing, had been reported by both patients and carers as being translated through the staff member behaviours in their practice of care giving. Reportedly staff members were respectful of the rights of the patient and their family/carers. Such as including both patients along with their family/carers when creating opportunities for education regarding the patient's disease, discussions and decisions made about the patient's process and healthcare planning. Patients and carers reported their inclusion had been exemplified by staff members, supporting patients and the roles of their family/carers, in their care planning. Patients and family/carers reported that being able to engage in assertive communication with staff members, had been an important factor needed to promote patients' and family's/carers' wellbeing.

Triangulation of the quantitative results, converge in association between the Mental Component Scale (MCS) and the ecology of healthcare. MCS as an indicator of mental wellbeing outcome for the patient is associated with the display of family strengths attributes by the SHDU staff members toward patients and family/carer. The patients mental wellbeing outcome is also associated with satisfaction of the own

family strengths. Together the relationships in the SHDU and the relationships within the family make up the ecology closest to the patient who is living with a VA.

The development of the individual in this CS, i.e. patients and family/carers required the support of the staff members and their family/carers through complex patterns and reciprocal activities. Where staff members and family/carers can provide the “scaffolding” for patients and family/carers through their strong bonds and or relationships with the individual by providing assistance (Damon & Lerner 2006) thus enabling the individual to develop, gain competency and independence.

### **Empowerment-empowered**

#### ***Statement two:***

The ecology of the SHDU empowering patient and family/carer participation in decision making according to individual preferences and goals may effectively promote satisfaction in healthcare and patient adherence to treatment regimens.

Participant responses, across all three groups had reported that patients are more effectively empowered when treated with respect as individuals. Patients and family/carers had reported that they had expected the right to be educated about the patient’s illness, healthcare treatments and the individuals healthcare planning. As a consequence it was necessary to enable patients and carers, to be empowered to make informed decisions about the patient’s care planning and care pathways and to enable patients to gain one’s independence through self-caring. As Curtin et al. (1997) suggest patients who require haemodialysis therapy, due to their ESKD are generally consigned to a life ruled by their adherence to a weekly routine of many hours of scheduled treatments, an extensive list of medications, dietary and fluid

restrictions to sustain their lives. Yet these patients still need to continue some sense of self mastery in their adherence to their medical regimen. This requires patients to manage a complex balance and yet avoid that the constant and time consuming demands of their individual healthcare regimens of therapies, medical appointments, symptoms and side effects of these treatments and ESKD, ruling and possibly ruining their lives.

With this in mind patients, family/carers and staff member responses had conveyed the concept of education to enable the patient to self-care, monitoring and caring for their VA and gain a greater level of independence. Through the course of patients' and carers' empowerment it was reported they had gained through their educational experiences. Participant responses had revealed that it was customary for the SHDU staff members to engage in sharing healthcare information with patients and family/carers. Patients and family/carers had reported that they expected to be kept informed. It was further identified through patient and family/carer responses, that they were in agreement with staff members, that empowerment was expanded through education which enabled patient and family/carer to have a voice to make informed decisions that included their personal choices. There are many important choices that need to be made both during the progression of a patient's CKD and then while living with ESKD. These decisions can have varied degrees of impact on the patients' and family's/carers' QOL and wellbeing. These life changing influences can be even more life challenging than the patient's clinical health outcomes (Goovaerts et al. 2015). Goovaerts et al. (2015) suggest it is crucial that the patient

and or family/carer are involved in the process of decision making, for their own satisfaction and to promote the patient's adherence to treatment regimens.

Patients and carers had shared that having assertive communication with staff members was necessary to voice their personal concerns and preferences when obliged to make choices about the patient's healthcare needs. This concept could have been further strengthened as a result of promoting a positive environment within this SHDU environment. Staff members had responded that maintaining a culture that appreciated patient and family/carer viewpoints had consequently, supported their empowerment. Patient empowerment included timely education which had been reported by one patient to be commenced primarily i.e. while the patient was in the final stages of CKD, before the patient had their first haemodialysis therapy. This standard of care giving was conveyed through participant responses, as being part of the culture embedded into the staff members care giving.

Enabling patients' and family's/carers' personal development to live with ESKD was seen to be more tolerable through their experience of empowerment and a culture of belonging within this SHDU community. These encouraging elements had been conveyed through patient, family/carer and staff member responses, as important factors that enabled patients to achieve a satisfactory level of wellbeing. Responses from across all three groups of participants had implied that staff members should endeavour to communicate effectively with patients. By acknowledging the patient's values, opinions, preferences and needs, which reportedly had suggested that these factors had been embedding into a staff member's practice of caring for this marginalised and potentially vulnerable

population of patients (Campbell-Crofts et al. 2013) and their family/carers. Patients, family/carers and staff members had been compelling in their accounts regarding the need to educate patients and carers to promote patients to be self-caring and thereby achieve a greater level of independence through their personal investment in acquiring knowledge for one's own empowerment.

Acknowledging patient and carer personal experiences of managing chronic diseases such as ESKD is an important factor when providing valuable information for health education, being 'an essential competency within the nursing role' (Campbell & Duddle 2010, p. 26). The SHDU staff members had reported they were responsible for education that supported patients and family/carers to be empowered to make informed choices relating to the patient's healthcare regimens to be self-caring and independent. One staff member had cautioned, the patient's team-healthcare professionals, should be empowered with sufficient knowledge and education to care for these patients appropriately. Correspondingly individualised planning of a patient's healthcare is a process. For this reason it is important that staff members who have direct contact with patients and family/carers provide support that assists these individuals in such a way that it enables them to work out what their goals are and then to support the patient and or family/carer to enable them to achieve these goals (Scerra 2012).

Triangulation of the quantitative results converges in association between patient empowerment and the ecology of healthcare. Patient empowerment as an indicator of a wellbeing outcome for the patient is associated with the display of family strengths attributes by the SHDU staff members towards patients and family/carers.

## **Patient comfort**

### ***Statement three:***

Achieving physical and psychological goals of personal comfort that enhance QOL and wellbeing may effectively enable patients to feel “normal”.

Patient comfort was a frequent theme throughout the responses of all three groups of participants. Although terms that had been utilised may have varied their representation related to patient's comfort throughout all three groups of participant responses, having conveyed the importance of maintaining a patient's comfort. Thus, enabling the patient to be happy, to cope and adapt (Bayoumi 2012) to manage their individual circumstances. As a theme patient comfort was embedded into care giving that enables a patient's comfort and contentment. Respondents had frequently expressed maintaining comfort as ensuring patients were happy.

Patients who retained a satisfactory level of one's normality had reported this enhanced one's own wellbeing. Participants had shared this required one to feel comfortable, the person's body felt normal, without all the added burdens of pain and disease, so as one would be able to carry on with their daily life. Able to complete personal activities of daily living (ADLs) continue working and hobbies. For these reason normality was reported as being normal of mind and being capable of completing physical activities. Patients had reported they would gain comfort and or be happy in their ability of continuing a life visiting friends, spending time with their family and attending social functions, being able to go for walks or shopping. Their ability to complete normal every day activities, that may ordinarily have been taken for granted, had inspired these patients to report they had gained pleasure from their



ability to maintain one's self-care and independence. Patients had reported that they measured their wellbeing upon how well they could achieve their daily activities.

Patients living with ESKD endure a myriad of painful experiences some of which are physical pain such as painful cannulations (Koncicke et al. 2015), joints, back pain, cramps and the discomfort of being immobile for lengthy periods of time while undergoing their haemodialysis therapy an accumulation of factors that result in patients experiencing tiredness and or fatigue (Bourbonnais & Tousignant 2012).

Patients experiencing moderate to severe pain have a higher prevalence of psychological issues such as depression, insomnia and are less able to cope with stress, experience increased irritability, increased symptom burden and reduced satisfaction with their life (Koncicki et al. 2015). Koncicki et al. (2015) reveal this group of patients are three times more likely to shorten treatment times and or withdraw from their haemodialysis therapy compared to patients who do not have these experiences. Understandably patients, carers and staff members had reported their concern as to what manner of care was delivered that would enable patient psychological and physical comfort. Reportedly this was seen as an important element in supporting patients to achieve a satisfactory level of wellbeing.

Accordingly, caring for patients had included being mindful of achieving an optimal level of patient comfort. Reportedly this concept was being supported by the actions of staff members and family/carers across all three groups of participants. As an example of this concept, was reported in how family/carers and staff members would engage with patients to check if they were happy and or endeavour to find ways to ensure the patient's comfort.

Staff members were reportedly mindful of enhancing patient comfort by the concept of remaining flexible with the patient haemodialysis therapy regimens to accommodate for patient and family/carers to continue a more normal family and social life. A family/carer had responded that they would follow initiatives that would provide their loved one comfort such as purchasing a remote control bed, organising holidays and helping the patient with their ADLs. Patients had reported that maintaining a routine of exercise was attributed as being normal to one's daily life and therefore important to one's wellbeing. In fact one's ability to exercise and complete ADLs was reported by patients to represent one's level of achievement of wellbeing.

Exercise has been suggested by Mitrou et al (2013), as an effective and safe non-pharmacological intervention for patients living with ESKD for the treatment of depression. They reported mental disorders were the most common co-morbidity for patients living with ESKD. Correspondingly patients may display poorer adherence to treatments and or are burdened with other side effect of renal impairment. Exercise has been encouraged both intra-dialytic (during haemodialysis therapy) with aerobic exercise programs reported as the most common (Bennet 2012). Inter-dialytic for non-dialysis days, exercises more commonly reported as varying from gentle walking, mild jogging, cycling and in some patients more vigorous exercises (Mitrou et al. 2013). Mitrou et al. (2013) propose common barriers to the popularity of exercise programs for people living with ESKD have been dependent on time, patient motivation and physical limitations and therefore require individualised programs for each patient, depending on the patient's physical demands (Bennett, P. 2012). Staff members and carers responses had repeatedly conveyed their support of patients

extending their level of mobility through encouraging and keenly helping patients to be active, self-caring and independent. Hence, helping patients to experience enhanced levels of comfort to feel “normal”.

Triangulation of the quantitative results converges in association between patient physical wellbeing and the ecology of healthcare. Physical Component Scale (PCS) as an indicator of physical wellbeing outcome for the patient is associated with the display of patient empowerment. The ecology of the SHDU community enhancing patient empowerment may enhance patient physical wellbeing outcomes, for example activities of self-caring and independence.

## **Vascular Access**

### ***Statement four:***

A patient’s experiences of living with a VA can include a burdening need to protect and care for this as their life-line, while being subjected to a routine of frequently painful cannulations.

A patient’s need to have a viable VA for their haemodialysis therapy can place both physical and psychological burdens on one’s life. Complications associated to patients’ VAs are common and result on around 30% of hospital admissions for patients living with a VA (Moist 2014). Patients, who had attended this particular SHDU community for their haemodialysis therapy, had reportedly by both patients and staff member responses, being educated to care for their VA and as a result had equally responded that they were aware of the consequences of such complications.

Enabling successful outcomes for patients living ESKD and a VA requires a multidisciplinary team approach that includes the patient and family/carers. Obtaining

a mature and viable VA patients and maintain the utility of a patient's VA, is the responsibility of everyone involved in the patient's care (Feddersen & Roger 2012). Through "the team" approach of a continuing dynamism of protecting, monitoring and surveillance of a patient's VA had reportedly, through both patient and staff member responses was aimed at promoting the utility and longevity of the patient's VA. Hence, reduce the risk of patients experiencing complications such as infection, thrombosis, surgical intervention and or failure of their VA.

Patients had shared their experiences of their need to take precautions in so far as their VA was concerned. Retaining such responsibilities was perceived by some patients as burdensome and as such had resulted in detrimental effects to one's physical and mental wellbeing. Firstly, patients had shared that they were required to remain constantly vigilant to guard against complications to their VA. Seemingly maintaining such responsibilities, had reportedly impacted on these patients everyday living. Thus, such responsibility had resulted in consequences to one's wellbeing. Secondly, one patient had reported their perception was that in having a VA, it had been symbolic of not being healthy.

The formation of a patient's VA for haemodialysis requires patients to have surgery. Complications associated with a patient's VA, can range from causing inconveniences to significant risks to a patients morbidity which can be significantly life threatening (Moist 2014). Should the patients VA fail to mature and or become problematic, further surgery may be required. As such, the viability of a patient's VA over extended periods of time can require multiple episodes of intervention and revisions. Surgery combined with repeated and varied cannulation techniques results

in scaring and aneurismal vessels, most commonly affecting the patient's arm and leg thigh or when a DCVC is utilised most often, the patient's chest and or neck. Such implications for VA formation inevitably results in vascular disturbances and to varying degrees results in deformities to the patient's body. These changes can affect one's personal perception of body image. Patients may feel unattractive and or unhealthy living within their own bodies (Muringai et al. 2008). Understandably one patient had responded that by having a VA for their haemodialysis therapy it had succeeded in improving their health status. As their VA had remained a permanent feature of their body however, it had not enhanced their perception of wellbeing.

Patients are burdened with the experience of their VAs being cannulated, generally with two needles each haemodialysis therapy session therefore thrice weekly. Patients living with ESKD, haemodialysis therapy and a VA can experience pain related to the procedure of their VA being cannulated, generally in their arm or leg thigh. Patients' experience of being "needled" with large gauge cannulas has been described as a horrible burning pain during insertion and or removal (Bourbonnais & Tousignant 2012). The patients had similarly reported that this can be a very difficult and painful experience and therefore reported, making a patient's life of attending the SHDU for their haemodialysis therapy, an uncomfortable encounter. Hence, as one patient has responded, you would not expect the SHDU to be a pain free zone. Another patient however, had reported the staff members had demonstrated that they were considerate of the patient's needs. Staff members had been supportive and had voiced their regret for having caused the patient discomfort. One patient had described being cannulated as the worst part of their haemodialysis

therapy, although had responded that as a result of staff members having displayed positive attitudes embedded within their care giving, this had helped them endure these painful experiences.

### **Context: Safe and friendly environment**

#### ***Statement five:***

A SHDU community that promotes an ecology of positive proximal processes can be supportive of both the patient's and their family's/carers' needs.

Participants had shared that supportive engagements between patients, family/carers and staff members enabled an individual's development. For this reason patients had relied on the support of other individual's i.e. family, friends, patients, carers and staff members to achieve a satisfactory level of wellbeing. Participants from each group had related their perceptions of the importance of patients having a safe and friendly environment to share for their haemodialysis therapy and care. Similarly it was suggested through the patients', family's/carers' and staff members' responses, these elements were perhaps a large part of the solution that enabled patients and family/carers to achieve their personal goals, required to reach one's satisfactory level of wellbeing.

A staff member had shared wellbeing concerned how you felt about yourself and therefore it was important, that the environments of one's communities supported patients' and family's/carers' positive experiences and or perspectives. The SHDU community and or the patient's immediate or larger community along with family and friends were both safe and friendly. Thus promoting positive aspects of a human's development and correspondingly to achieve one's satisfaction of QOL and

wellbeing. The patients, family/carers and staff members had shared as a comparable requirement, that the SHDU community was a safe and friendly environment.

Promoting a culturally welcoming community that would more readily provide support of a patient's and family's/carers' individual needs. Participants had shared in their responses a confirmation that this was the case. For example, one staff member had reported that it was important for patients and family/carers wellbeing that they had confidence in both the staff and resources of the SHDU. Staff members had encouraged patients and family/carers to socialise within the SHDU community as well as continuing their social involvement within their wider communities, along with family and friends. Staff members had maintained a level of flexibility within patients' schedules of haemodialysis therapy, to allow patients to continue their social interactions away from the SHDU community.

Participant responses by and large had confirmed that support systems were achieved through family, friends and SHDU staff members having provided patients and family/carers with safe and friendly environments. Participants from each of the three groups i.e. patients, family/carers and staff members had reported that the SHDU staff members had delivered healthcare practices that had been embedded with strong values of caring. For this reason, staff members had reported they had encouraged a culturally friendly environment that provided valuable emotional support for patients and their family/carers to feel safe within, this SHDU community.

## **Time:**

### ***Statement six:***

Patients and family/carers becoming comfortable with living with changes necessary to maintain the utility of the patient's life-line can develop over lengthy periods of time.

Haemodialysis therapy can prolong the life of most patients. Patients living with ESKD however, generally have a shortened life circle and for many individuals this becomes an existence which combines significant burdens of the disease process, haemodialysis therapy, relying on a VA and the care of others featuring in their everyday life (Madhan 2010). Patients and their family/carers regularly spend time experiencing a constant weekly "loop" of treatment regimens, hospitalisations and surgical procedures and or suffering complications.

It has been identified that patients can try to adapt their regimens or even manipulate the "system" to gain some higher level of autonomy, as a sense of independence and to have some level of control over time (Curtin et al. 1997). There were no reports however, that suggested this concept among participant responses. In spite of the burdens that the patients and family/carers experienced, a staff member had reported that some patients had conveyed that they were able to accept their circumstances and were happy that there was haemodialysis therapy available to sustain the lives. Patients had communicated that they had embraced activities that promoted their wellbeing.

Patients and family/carers had communicated within their responses, that wellbeing had perhaps represented elements of a patient's health that may have once upon a time, been more fully enjoyed and then to some degree the patient had



suffered from their loss. Patients' and family's/carers' responses had emerged as a reflection of living with ESKD, haemodialysis therapy and a VA.

To enhance patient outcome and therefore patient and family/carer QOL and wellbeing, patients and family/carers would optimally begin their preparation for the patient's VA (Feddersen & Roger 2012) and education would commence before patients had started haemodialysis therapy. At the later stages of the patient's CKD referred to as 3b and early stage 4, primary healthcare professionals would refer patients to a nephrologist allowing time to minimize complications and the progression of a patient's CKD (Polkinghorne et al. 2013). This initiative correspondingly provides patients and family/carers with an advantage of ample time to make informed choices that are clinically appropriate for them (Muringai et al. 2008). Muringai et al. (2008) explain that choosing dialysis options is a complex matter as it involves major changes to one's lifestyle. Patients lead a life that depends on treatments such as haemodialysis therapy and therefore the successful surgical creation, maturation and ongoing maintenance of their VA. To remain complication free and hence viable as the patient's dedicated life-line. Otherwise the patient's QOL and wellbeing or even their very existence would not be able to be sustained.

Patients had reported that endurance of pain was just one of the burdens of having a VA. One patient had reported that after the experience of painful complications which had resulted in the failure of their previous AVF, this patient had reported they would remain watchful. This was to ensure that a similar experience such as failure of this patient's new AVF, was not due to another traumatic cannulation. This was an experience the patient conjectured through their own

vigilance, was an experience that was not going to be repeated. Correspondingly, patients had also reported that being required to be mindful of their VA at all times had negative impacts on their QOL and wellbeing. Such experiences had reportedly discouraged patients, by feeling the need to sustain from certain activities. Patients had responded that they were unable to complete their ADLs and had felt as though they were different and were not normal. As an example, a patient had responded that their VA had signified to them that they were unwell.

Time was seen as allowing for some level of tolerance with the more unfavourable elements of living with ESKD including changes to a patient's body and correspondingly to the patients and family/carers lives. Through a period of transition patients had reported one's perceptions had also changed over lengthy periods of time. An example of this was one patient, who had reported that in consideration of living with their VA and being required to take care of it as their life-line they had succumb to an eventual acceptance of this task and the ensuing changes to their body. The patient had reported from their experience of having had their VA over a lengthy period of time, they had eventually become "happy" with it.

Bronfenbrenner theory had been extended during later years, to include form, power, content and direction of proximal processes. The effect on a human's development is a joint function of both their immediate and remote environments, in which these processes take place and as such changes occur systematically within the characteristics of a developing individual (Bronfenbrenner & Ceci 1994). The developmental nature of a human being occurs throughout their life-span and therefore is seen over time (seen as the chronosystem of Bronfenbrenner's PPCT

model, see Appendix 1.' The bioecological model') through social continuities and changes (Tudge et al. 2009). As participants had reported living with ESKD they had learnt to change and adapt (Bayoumi 2012) their lives over time.

The PPCT model reemphasizes developmental transformation and the individual in context over time (Tudge et al. 2009). Time for this group of patients and their family/carers had become an important concept being a precious commodity in their lives.

The qualitative results of this case have revealed stories within patients' response to the open ended questions triangulated with the quantitative results converged to develop six statements. These six statements conceptualise the results in a new synthesis of understanding the phenomena of care of a patient's VA for haemodialysis.

## **Limitations**

This CS explored the bioecology of one SHDU community and therefore a small number of participants. It is necessary for CSs to subsequently explore a diverse range of haemodialysis care facilities, for example an investigation that includes multiple units of both rural and international facilities to test the findings of this CS. Demographic information was limited so that participants remained non-identifiable. This resulted in the inability for the results to be verified by the participants. Patient inclusion criteria was only that patients required RRT for their ESKD and therefore were receiving haemodialysis therapy via a VA of an AVF or AVG, which required cannulation to access their cardio-vascular system for their haemodialysis therapy regimen. Potentially identifying information such as patient age, gender, co-

morbidities and medical history were not obtained. Similarly there was no information acquired concerning the relationship between patients and their family/carers. Likewise information regarding staff member demographics was not obtained to maintain anonymity.

This CS relied exclusively on questionnaires for collation of data, which may not have provided as much information as interviews. Although participant interviews prevents anonymity, utilisation of open ended questions during such interviews can initiate responses that are non-restricted and free flowing as they may encourage participants to volunteer more information (Edwards et al. 2014). Although, guarding participants' anonymity may have also enabled some individuals to respond more openly within their written responses.

Qualitative researchers conducting interviews have the opportunity for member checking with participants, either through transcribed interviews and or completed data analysis (Morse et al. 20015). Doyle (2007) utilised member checking as a methodological style to develop a consistent participatory approach and active negotiation of meaning. As Morse et al. (2015) explain member checking is a process which allows participants to check their data is correct, change their mind and or provide additional information however, this can be problematic. This may not be practical. The researcher's analysis is generally a synthesis of multiple interviews and a single participant would be less likely to recognise their own story and should the participant disagree it can cause tensions in the investigator-participant relationship. It is however, the investigators decision by relying on their own investigative

background and theory to judge the qualitative analysis and therefore Morse et al. (2015) do not recommend this strategy.

Kendall rank coefficient of concordance of the Family Satisfaction Scale (FSC) and the patient Empowerment Scale Current (FSC) revealed a slightly lower correlation however, this may have been in consequence to (at least two) patients having revealed, that as their family members, live some distance away from them and as a result of these personal circumstances they were self-caring, relied on staff members and or friends for their supportive needs. QOL for patients whose lives are burdened with ESKD is not one-dimensional (Kastrouni et al. 2010). ESKD bears potential influences on a patient's physical and psychological health, functionality, independence, personal relationships and their ability to function socially (Cleary & Drennan 2005). Correspondingly, participating patients had frequently responded, expressing their appreciation of supportive family members and friends who had helped patients to manage the burden of their ESKD and complex treatment regimens, by feeling loved. These are elements which the patients and family/carers had conveyed as being a necessity to enriching one's QOL and wellbeing.

## **Conclusion**

The aim of this CS was to understand the role and influences of nursing care that supports patients and their families and friends as carers, to maintain the viability of the patient's VA in a SHDU. From the initial discussions during meeting at the SHDU, with the NUM and subsequent participant responses to questionnaires, it had been exhibited that the SHDU functioned as a community. It was also communicated by the SHDU nurse unit manager during the first meeting, the organisational culture of

the SHDU community was based on routines. A supportive culture promoted knowledge acquisition, hence empowering patients and family/carers within activity routines of patient care. An important element of patient care however, included the staff members maintained an organisational culture that encouraged flexibility in a patient's haemodialysis routine to accommodate the patient's and family's/carers' needs for a normal family and social life. This concept emphasised the importance of retaining complex and sometimes paradoxical cultures in organisations within healthcare which supports change within safe boundaries (Albarbi et al. 2014). As a result, this SHDU community promoted the patient's and family's/carers' empowerment for their realisation of personal goals of QOL, as an outcome of care. Chapter eight will present the conclusion and recommendation arising from this CS.

## **CHAPTER EIGHT: CONCLUSION**

This investigation was a CS of one SHDU community. The CS explored the interactions between patients, their family and friends as carers and staff members within the SHDU. It is not intended for this case study to be representative of other SHDU environments however, the findings from this case study through a bioecological perspective, provided further insight into the factors influencing the management and care of a patient with a VA as an essential component required for their haemodialysis therapy.

Participants in this CS demonstrated their individual roles had included active participation within the SHDU community. Patients' and family's/carers' relationship with the SHDU staff members were an important element of achieving a self-reported satisfactory level of wellbeing.

Participants across all three groups identified that involving patient and family/carers in decision making processes can have an impact on patients' and family's/carers' QOL and wellbeing. This finding supports Goovaerts et al. (2015) who propose it is crucial that the patient and or family/carers are involved in the process of decision making, for their own satisfaction and to promote the patient's adherence to treatment regimens. As the patient's and family's/carers' experiences of living with ESKD, their QOL is frequently experienced as a multi-dimensional complexity of a progressive and debilitating chronic illness requiring ongoing care and medical interventions (Cleary & Drennan 2005). Therefore, the patient's QOL and wellbeing and those of their family's/carers' (within their own roles), are associated with a complexity of interacting factors of dysfunction in a multitude of aspects (Kastrouni et

al. 2010). The results of this CS however, have demonstrated patient and family/carers involvement in decision making had enabled their ability to live with ESKD seem more tolerably.

Patients along with their family/carers who are living with ESKD and a chronic routine of medical treatments, including haemodialysis therapy requiring a viable VA, find themselves in a highly complex and chronic situation. This frequently challenges the patient's and their family's/carers' available resources within their ecology and consequently their ability to manage their personal circumstances. Therefore, healthcare professionals need to be mindful of how they can help patients and their family/carers, to be in control of, and participate in decision making and care regimens. Importantly empowerment for this group of patients was revealed to be a significant element contributing to wellbeing.

### **Recommendation arising from the study**

This research recommends that practice guidelines which concentrate on the biological factors for care should now be supported by bioecological domains of nursing care.

Currently, clinical practice guidelines (CPGs) and clinical practice recommendations (CPRs) address patients' VA care on a level which relates biological factors drive patient care outcomes. Therefore, current CPGs and CPRs are not comprehensive as they do not appear to value a person's as an individual and their experiences of healthcare or perceptions of their care wishes. Hence, they do not incorporate factors associated with the experiences of the patients, as well as



the patient's family and friends as carers (within their own roles) along with the ecology of the care environment, in principal the SHDU community.

Relationships, roles and environment of care (together known as the ecology) are important elements in providing holistic and optimal care that is both empowering and respectful. Further evidence is required to understand the association between the ecology of healthcare and the patient's and family's/carers' quality of life, as an outcome of patient care.

Importantly, research supports that integrating evidence into clinical practices, enhances patients' care through the development of evidenced based CPGs (Melnik et al. 2014). CPGs need to maximise applicability to practice and are dependent on strength of evidence and recommendations, being balanced on benefit versus risk to the patient, burden and cost (Fluck & Kumwenda 2011). As MacPhail et al. (2015) advise inappropriate treatment is 'defined as treatment that is ineffective, harmful, or excessively burdensome, or not consistent with patients' wishes' (p. 2). CPGs within the context of caring Melnyk et al. (2014) advise, is when clinical decision making is a holistic integration of research evidence and evidence-based theories, clinical expertise and evidence combined from assessment of the patient's history-condition, healthcare resources and patients' preferences and values. Consequently Fluck & Kumwenda 2011 recommend that CPGs-EBPs are required to provide considerable direction to healthcare professionals, patients and family and friends as carers to effectively enhance the patient's health outcomes, QOL and wellbeing. Through optimizing the quality, safety and reliability of healthcare improves patients' health outcomes, and 'reduces variations in quality of care and costs' (Melnik et al. 2014, p.

5), to the patient, their family and friends as carers, the community and the healthcare system.

The management of a patient's VA for effective haemodialysis therapy is complicated requiring optimal techniques of VA surveillance, monitoring, cannulation techniques together with understanding the bioecological factors and elements. Combined, these can be understood and addressed appropriately, to positively influence the viability and therefore the longevity of the patient's VA, and as a consequence the patient's healthcare outcomes and QOL. Importantly, healthcare professionals including nurses have the opportunity to work together evolving strong relationships in partnership with the patient, their family and friends as carers to implement CPGs and CPRs that focus on a holistic team orientated approach to patients' VA care. This holistic approach embraces a model of shared-care of the patient's VA and as a result has the potential to enhance patients' healthcare including nursing practices and resulting patient outcomes.

The aim of this CS was to understand the role and influences of nursing care that supports patients and family/carers to maintain the viability of the patient's VA in a satellite haemodialysis unit as a community. This investigation revealed associations between the ecology within the SHDU community and the patients' healthcare outcomes. Time for these patients and family/carers is a precious commodity associated with the chronicity of the patient's healthcare needs. As a result of their kidney disease and frequent co-morbidities, patients' lives become a complexity of ESKD and treatment regimens including haemodialysis. Importantly,

a patient's life journey becomes an ongoing struggle to achieve personal goals and maintain the longevity and viability of their VA.

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## REFERENCES

- Aasen, E.M., Kvangarsnes, M., Wold, B. & Heggen, K. 2012, 'The next of kin of older people undergoing haemodialysis: a discursive perspective on perceptions of participation', *Journal of Advanced Nursing*, vol. 68, no. 8, pp. 1716-1725, viewed 28 October 2012, via Wiley Online.
- Abdelhafiz, A.H., Bailey, C., Russell, J. & El Nahas, M. 2013, 'Chronic kidney disease in older people', *Reviews in Clinical Gerontology*, vol. 23, no. 3, pp. 177-188, viewed 21 October 2013, via ProQuest
- Al-Jaishi, A., Oliver, M., Thomas, S., Lok, C., Zhang, J., Garg, A., Kosa, S., Quinn, R. & Moist, L. 2013, 'Original investigation: Patency rates of the arteriovenous fistula for hemodialysis: A systematic review and meta-analysis', *American Journal of Kidney Diseases*, vol. 63, no. 3, pp. 464-478, viewed 22 February 2014, via ScienceDirect.
- Alharbi, T.S.J., Olsson, L.-E., Ekman, I. & Carlström, E. 2014, 'The impact of organizational culture on the outcome of hospital care: After the implementation of person-centred care', *Scandinavian Journal Of Public Health*, vol. 42, no. 1, pp. 104-110, viewed 29 January 2015, via MEDLINE.
- Allon, M., Litovsky, S., Young, C.J., Deierhoi, M.H., Goodman, J., Hanaway, M., Lockhart, M.E. & Robbin, M.L. 2013, 'Correlation of pre-existing vascular pathology with arteriovenous graft outcomes in hemodialysis patients', *American Journal of Kidney Diseases*, vol. 62, no. 6, pp. 1122-1129, viewed 5 April 2014, via ScienceDirect.
- Amerson, R. 2011, 'Making a case for the case study method', *Journal of Nursing Education*, vol. 50, no. 8, pp. 427-428, viewed 13 December 2012, via ProQuest
- Anthony, S. & Jack, S. 2009, 'Qualitative case study methodology in nursing research: An integrative review.', *Journal of Advanced Nursing*, vol. 65, no. 6, pp. 1171-1181, viewed 16 December 2012, via CINAHL.
- ANZDATA 2013, *Appendix.B: Prevalent Data 2012. Table: B2*, ANZDATA Registry, Adelaide, Australia, viewed 2 January 2014, <[http://www.anzdata.org.au/v1/report\\_2013.html](http://www.anzdata.org.au/v1/report_2013.html)>.
- Arnold, K.D., Lu, E.C. & Armstrong, K.J. 2012, 'The human ecology framework', *The Ecology of College Readiness: ASHE Higher Education Report* vol. 38, no. 5, pp. 11-18, viewed 24 July 2014, via Wiley Online.
- Ayoub, A., Nelson, K., Wood, P. & Hijjaza, K. 2014, 'The relationship between laboratory values and quality of life of dialysis patients in United Arab Emirates', *The*

*Renal Society of Australasia Journal*, vol. 10, no. 1, pp. 12-20, viewed 17 March 2014, via ProQuest.

Ball, L.K. 2005, 'Improving arteriovenous fistula cannulation skills', *Nephrology Nursing Journal*, vol. 32, no. 6, pp. 611-617, viewed 23 August 2010, via CINAHL.

Barnes, T., Hancock, K. & Dainton, M. 2013, 'Training nurses to support greater patient engagement in haemodialysis', *Journal of Renal Care*, vol. 39, no. Supplement 2, pp. 10-18, viewed 2 October 2013, via CINAHL.

Bayoumi, M. 2012, 'Identification of the needs of haemodialysis patients using the concept of Maslow's hierarchy of needs', *Journal of Renal Care*, vol. 38, no. 1, pp. 43-49, viewed 19 December 2014, via CINALH.

Beanlands, H., Horsburgh, M.E., Fox, S., Howe, A., Locking-Cusolito, H., Pare, K. & Thrasher, C. 2005, 'Caregiving by family and friends of adults receiving dialysis', *Nephrology Nursing Journal*, vol. 32, no. 6, pp. 621-631, viewed 18 October 2012, via ProQuest.

Bennett, A. 2001, 'Case study: Methods and analysis', in N Smelser & P Baltes (eds), *International Encyclopedia of the Social & Behavioral Sciences*, 2nd edn, Pergamon, Oxford, vol. 3, pp. 1513-1519, viewed 15 December 2012, via ScienceDirect.

Bennett, P. 2011, 'Satellite dialysis nursing: technology, caring and power', *Journal of Advanced Nursing*, vol. 67, no. 1, pp. 149-157, viewed 22 July 2011, via Wiley Online.

Bennett, P. 2012, 'Exercise adequacy in dialysis', *The Renal Society of Australasia Journal*, vol. 8, no. 2, pp. 52-53, viewed 2 August 2012, via ProQuest.

Bennett, P. & Neill, J. 2008, 'Quality nephrology nursing care: beyond Kt/V', *Nephrology Nursing Journal*, vol. 35, no. 1, pp. 33-37, viewed 22 July 2011, via CINAHL.

Bergen, A. & While, A. 2000, 'A case for case studies: exploring the use of case study design in community nursing research', *Journal of Advanced Nursing*, vol. 31, no. 4, pp. 926-934, viewed 4 January 2013, via Wiley Online.

Bergman, M. 2011, 'The good, the bad, and the ugly in mixed methods research and design', *Journal of Mixed Methods Research*, vol. 5, no. 4, pp. 271-275, viewed 15 December 2012, via SAGE Journals.

Bessias, N., Paraskevas, K., Tziviskou, E. & Andrikopoulos, V. 2008, 'Vascular access in elderly patients with end-stage renal disease', *International urology and*

*nephrology*, vol. 40, no. 4, pp. 1133-1142, viewed 1 December 2008, via Springer Link.

Bonner, A. & Lloyd, A. 2011, 'What information counts at the moment of practice? Information practices of renal nurses', *Journal of Advanced Nursing*, vol. 67, no. 6, pp. 1213-1221, viewed 23 June 2011, via CINAHL.

Bonner, A., Wellard, S. & Caltabiano, M. 2010, 'The impact of fatigue on daily activity in people with chronic kidney disease', *Journal of Clinical Nursing*, vol. 19, no. N/a, pp. 3006-3015, viewed 16 July 2011, via CINAHL.

Boon, H., Cottrell, A., King, D., Stevenson, R. & Millar, J. 2012, 'Bronfenbrenner's bioecological theory for modelling community resilience to natural disasters', *Natural Hazards*, vol. 60, no. 2, pp. 381-408, viewed 15 April 2014, via Springer Link.

Bosch, M., Tavender, E., Bragge, P., Gruen, R. & Green, S. 2012, 'How to define 'best practice' for use in knowledge translation research: a practical, stepped and interactive process', *Journal of Evaluation in Clinical Practice*, vol. 19, no. 5, pp. 763-768, viewed 12 May 2012, via Wiley Online.

Bourbonnais, F.F. & Tousignant, K.F. 2012, 'The pain experience of patients on maintenance hemodialysis', *Nephrology Nursing Journal*, vol. 39, no. 1, pp. 13-19, viewed 23 April 2014, via CINAHL.

Bowen, S. & Martens, P. 2005, 'Demystifying knowledge translation: learning from the community', *Journal of Health Services Research & Policy*, vol. 10, no. 4, pp. 203-211, viewed 15 April 2014, via ProQuest.

Brathovde, A., Bodine, J., Cagliostro, J., Lopresti, L., Perumpail, L. & Palisoc, V. 2013, 'Using reflective journaling to establish a holistic nursing practice council', *International Journal for Human Caring*, vol. 17, no. 2, pp. 35-38, viewed 18 October 2015, via CINAHL.

Braun, V. & Clarke, V. 2006, 'Using thematic analysis in psychology', *Qualitative Research in Psychology*, vol. 3, no. 2, pp. 77-101, viewed 14 May 2012, via ProQuest.

Bronfenbrenner, U. 1979, *The ecology of human development. Experiments by nature and design*, Cambridge: Harvard University Press

Bronfenbrenner, U. 2001, 'Bioecological theory of human development', in J Neil & B Paul (eds), *International Encyclopedia of the Social & Behavioral Sciences*, Permagon, Oxford, pp. 6963-6970.

Bronfenbrenner, U. 2005, *Making human beings human : bioecological perspectives on human development*. Thousand Oaks : Sage Publications.

Bronfenbrenner, U. & Ceci, S. 1994, 'Nature-nurture reconceptualized in developmental perspective: A bioecological model', *Psychological Review*, vol. 101, no. 4, pp. 568-586, viewed 18 July 2012, via Scopus.

Bronfenbrenner, U. & Ceci, S.J. 1993, 'Heredity, environment and the question "How"? A first approximation. ', in *In R. Plomin & G. G. McClearn (Eds.), Nature, nurture, and psychology.*, American Psycho-logical Association, Washington, DC, pp. 313-323.

Bronfenbrenner, U. & Morris, P.A. 1998, 'The ecology of developmental processes. In W. Damon (Ed.-in-Cheif) and R. M. Lerner (Vol. Ed. and Ed.-in-Cheif)', in *Handbook of Child Psychology: Vol. 1. Theoretical Models of Human Development 5th ed.*, Wiley, New York, pp. 993-1027.

Brophy, S. 2008, 'Making the case for case study research', *Kai Tiaki Nursing New Zealand*, vol. 14, no. 11, pp. 20-22, viewed 18 December 2012, via CINAHL.

Brouwer, D. 2005, 'Needle placement is paramount to achieving effective dialysis and preserving vascular accesses', *Nephrology Nursing Journal*, vol. 32, no. 2, pp. 225-227, viewed 25 September 2011, via ProQuest.

Brown, L. & Harvie, B. 2010, 'Nephrology nurse practitioners: making a difference', *Renal Society of Australasia Journal*, vol. 6, no. 3, p. 101, viewed 3 December 2010, via ProQuest.

Brown, M.A., Crail, S.M., Masterson, R., Foote, C., Robins, J., Katz, I., Josland, E., Brennan, F., Stallworthy, E.J., Siva, B., Miller, C., Urban, A.K., Sajiv, C., Glavish, R.N., May, S., Langham, R., Walker, R., Fassett, R.G., Morton, R.L., Stewart, C., Phipps, L., Healy, H. & Berquier, I. 2013, 'ANZSN Renal Supportive Care Guidelines 2013', *Nephrology*, vol. 18, no. 6, pp. 401-454, viewed 21 September 2013, via Wiley.

Bryman, A. 2007, 'Barriers to integrating quantitative and qualitative research', *Journal of Mixed Methods Research*, vol. 1, no. 1, pp. 8-22, viewed 15 December 2012, via SAGE Journals.

Campbell-Crofts, S., Field, J. & Fetherstonhaugh, D. 2013, 'Ethical considerations for nurses undertaking research with a potentially vulnerable population with chronic kidney disease', *Renal Society of Australasia Journal*, vol. 9, no. 2, pp. 74-79, viewed 10 March 2014, via ProQuest Central.



Campbell, S. & Duddle, M. 2010, 'Health literacy in chronic kidney disease education', *The Renal Society of Australasia Journal*, vol. 6, no. 2, pp. 26-31, viewed 28 July 2011, via ProQuest.

Casey, D. & Houghton, C. 2010, 'Clarifying case study research: examples from practice', *Nurse Researcher*, vol. 17, no. 3, pp. 41-51, viewed 14 April 2013, via ProQuest

Castro, F., Kellison, J., Boyd, S. & Kopak, A. 2010, 'A methodology for conducting integrative mixed methods research and data analyses', *Journal of Mixed Methods Research*, vol. 4, no. 4, pp. 342-360, viewed 15 December 2012, via SAGE journals.

Chaiklin, H. 2000, 'Doing case study research', *American Journal of Dance Therapy*, vol. 22, no. 1, pp. 47-59, viewed 5 January 2013, via SpringerLink.

Chamney, M., Cook, T., Das, R., Muhammad, S. & Jones, J. 2012, 'Renal health care professionals patient and carers collaboration to improve education and research ', *Renal Society of Australia Journal*, vol. 8, no. 3, pp. 120-125, viewed 12 November 2012, via ProQuest.

Chandra, A., Dimascio, D., Gruenewald, S., Nankivell, B., Allen, R. & Swinnen, J. 2010, 'Colour duplex ultrasound accurately identifies focal stenoses in dysfunctional autogenous arteriovenous fistulae', *Nephrology*, vol. 15, no. 3, pp. 300-306, viewed 12 August 2011, via Wiley Online

Chanouzas, D., Ng, K.P., Fallouh, B. & Baharani, J. 2012, 'What influences patient choice of treatment modality at the pre-dialysis stage?', *Nephrology Dialysis Transplantation*, vol. 27, no. 4, pp. 1542-1547, viewed 11 June 2013, via Oxford Journals.

Cho, E.J., Park, H.C., Yoon, H.B., Ju, K.D., Kim, H., Oh, Y.K., Yang, J., Hwang, Y.-H., Ahn, C. & Oh, K.-H. 2012, 'Effect of multidisciplinary pre-dialysis education in advanced chronic kidney disease: propensity score matched cohort analysis', *Nephrology*, vol. 17, no. 5, pp. 472-479, viewed 29 October 2012, via Wiley Online.

Chow, J., Rayment, G., Miguel, S.S. & Gilbert, M. 2011, 'A randomised controlled trial of buttonhole cannulation for the prevention of fistula access complications', *Journal of Renal Care*, vol. 37, no. 2, pp. 85-93, viewed 12 August 2011, via CINAHL.

Clarkson, K.A. & Robinson, K. 2010, 'Life on dialysis: A lived experience', *Nephrology Nursing Journal*, vol. 37, no. 1, pp. 29-35, viewed 25 September 2012, via ProQuest.

Cleary, J. & Drennan, J. 2005, 'Quality of life of patients on haemodialysis for end-stage renal disease', *Journal of Advanced Nursing*, vol. 51, no. 6, pp. 577-586, viewed 19 September 2012, via Wiley Online.

Couchoud, C.G. 2015, 'Development of a risk stratification algorithm to improve patient-centered care and decision making for incident elderly patients with end-stage renal disease', *Kidney International*, vol. 88, no. 5, pp. 1178-1186, viewed 9 December 2015, via CINAHL.

Cowan, D. 2016, 'Understanding the journey travelled by patients and carers living with end stage kidney disease and haemodialysis' *Australian Nursing and Midwifery Journal*, vol. 23, no. 8, pp. 26-29, viewed 15 March 2016, via EBSOHOST.

Cowan, D., Smith, L. & Chow, J. 2016 (first published online 30 September 2015) 'Care of a patient's vascular access for haemodialysis: A narrative literature review.', *Journal of Renal Care*, vol. 42, no. 2, pp. 93-100, viewed 30 September 2015, via Wiley Online.

Cowan, D., Smith, L. & Chow, J. 2016, 'Maintaining a viable vascular access for haemodialysis in an elderly person with diabetes: A journey to live, not just to stay alive.', *Clinical Case Reports*, vol. 4, no. 2, pp. 203-208, viewed 4 January 2016, via Wiley Online Open Access.

Craig, J. & Smyth, R. (eds) 2007, *The evidence-based practice manual for nurses* 2nd edn, Churchill Livingstone Elsevier, London.

Creswell, J. & Tashakkori, A. 2008, 'Editorial: How do research manuscripts contribute to the literature on mixed methods?', *Journal of Mixed Methods Research*, vol. 2, no. 2, pp. 115-120, viewed 15 December 2012, via SAGE journals.

Creswell, J.W. & Plano Clark, V.L. 2007 [i.e. 2006], *Designing and conducting mixed methods research*, 1 edn, Thousand Oaks, Calif: SAGE Publications.

Curtin, R., Oberley, E. & Sacksteder, P. 1997, 'Compliance and rehabilitation in ESRD patients', *Seminars in Dialysis*, vol. 10, no. 1, pp. 52-54, viewed 3 March 2013, via Wiley Online.

Damon, W. & Lerner, R.M. 2006, *Handbook of child psychology*, 6 edn, vol. 1, Theoretical Models of Human Development: Hoboken, N.J. : John Wiley & Sons.

Darling, N. 2007, 'Ecological systems theory: The person in the center of the circles', *Research in Human Development*, vol. 4, no. 3/4, pp. 203-217, viewed 22 April 2014, via SocINDEX.

de Leur, K., Öztürk, Ç., Van Zeeland, M.L.P., de Groot, H.G.W., Heyligers, J.M.M., Vriens, P.W.H.E., Ho, G.H. & van der Laan, L. 2013, 'Vascular access outcome in the elderly dialysis patient in combination with the quality of life', *Vascular and*

*Endovascular Surgery*, vol. 47, no. 6, pp. 444-448, viewed 25 August 2013, via SAGE Journals.

DeFrain, J. & Asay, S. 2007, 'A strengths-based conceptual framework for understanding families world-wide', in JDS Asay (ed.), *Strong families around the world. Strengths-based research and perspectives*, The Haworth Press, New York, pp. 447-466.

Dinwiddie, L.C., Ball, L., Brouwer, D., Doss-McQuitty, S. & Holland, J. 2013, 'What nephrologists need to know about vascular access cannulation', *Seminars in Dialysis*, vol. 26, no. 3, pp. 315-322, viewed 25 June 2013, via Wiley Online.

Doyle, S. 2007, 'Member checking with older women: a framework for negotiating meaning', *Health Care for Women International*, vol. 28, no. 10, pp. 888-908, viewed 10 December 2015, via CINAHL.

Edwards, K.J., Duff, J. & Walker, K. 2014, 'What really matters? A multi-view perspective of one patient's hospital experience', *Contemporary Nurse*, vol. 49, no. 49, pp. 122-136, viewed 20 June 2015, via CINAHL.

Evans, D., Gruba, P. & Zobel, J. 2011, *How to write a better thesis*, 3rd edn, Australia: Melbourne University Press.

Fahrtash, F., Kairaitis, L., Gruenewald, S., Spicer, T., Sidrak, H., Fletcher, J., Allen, R. & Swinnen, J. 2011, 'Defining a significant stenosis in an autologous radio-cephalic arteriovenous fistula for hemodialysis', *Seminars in Dialysis*, vol. 24, no. 2, pp. 231-238, viewed 2 September 2011, via Wiley Online.

Feddersen, M.A. & Roger, S.D. 2012, 'Arteriovenous fistula surveillance: Everyones responsibility', *Portuguese Journal of Nephrology & Hypertension*, vol. 26, no. 4, pp. 255-265, viewed 09 September 2013, via SciELO.

Field, A. 2005, *Discovering statistics using SPSS: (and sex, drugs and rock 'n' roll)*, London: Sage.

Fluck, R. & Kumwenda, M. 2011, 'Renal association clinical practice guideline on vascular access for haemodialysis', *Nephron*, vol. 118, no. Supplement S1, pp. 225-240, viewed 2 July 2012, via ProQuest

Flyvbjerg, B. 2006, 'Five misunderstandings about case-study research', *Qualitative Inquiry*, vol. 12, no. 2, pp. 219-245, viewed 5 January 2013, via SAGE Journals.

Fresenius Medical Care 2011, *ESRD Patients in 2011. A Global Perspective*, Fresenius Medical Care, Germany, viewed 8 May 2015, <[http://www.vision-fmc.com/files/download/ESRD/ESRD\\_Patients\\_in\\_2011.pdf](http://www.vision-fmc.com/files/download/ESRD/ESRD_Patients_in_2011.pdf)>.

Freshwater, D. & Cahill, J. 2012, 'Why write', *Journal of Mixed Methods Research*, vol. 6, no. 3, pp. 151-153, viewed 14 May 2013, via SAGE Journals.

Friborg, O. & Rosenvinge, J.H. 2013, 'A comparison of open-ended and closed questions in the prediction of mental health', *Quality & Quantity*, vol. 47, no. 3, pp. 1397-1411, viewed 14 September 2015, via Science Citation Index.

Gangeness, J. & Yurkovich, E. 2006, 'Revisiting case study as a nursing research design', *Nurse Researcher*, vol. 13, no. 4, pp. 7-18, viewed 4 January 2013, via ProQuest.

Gillham, B. 2000, *Case study research methods*, London: Continuum.

Godbold, N. 2013, 'Tensions in compliance for renal patients – how renal discussion groups conceive knowledge and safe care', *Health Sociology Review*, vol. 22, no. 1, pp. 52-64, viewed 21 September 2013, via informit.

Goovaerts, T., Bagnis Isnard, C., Crepaldi, C., Zambon, R., Dean, J., Melander, S., Mooney, A., Prieto-Velasco, M., Trujillo, C. & Nilsson, E.L. 2015, 'Continuing education: Preparing patients to choose a renal replacement therapy', *Journal of Renal Care*, vol. 41, no. 1, pp. 62-75, viewed 03 January 2015, via Wiley Online.

Green, B., Johnson, C. & Adams, A. 2006, 'Clinical Update: Writing narrative literature reviews for peer-reviewed journals: Secrets of the trade', *Journal of chiropractic medicine*, vol. 5, no. 3, pp. 101-117, viewed 12 June 2013.

Green, L. 2008, 'Making research relevant: if it is an evidence-based practice, where's the practice-based evidence?', *Family Practice*, vol. 25, no. suppl 1, pp. i20-i24, viewed 27 January 2013, via Oxford Journals.

Guest, G. 2012, 'Describing mixed methods research: An alternative to typologies', *Journal of Mixed Methods Research*, vol. 7, pp. 141-151, viewed 1 April 2013, via Sage Journals.

Hagren, B., Pettersen, I., Severinsson, E., Lützén, K. & Clyne, N. 2005, 'Maintenance haemodialysis: patients' experiences of their life situation', *Journal of Clinical Nursing*, vol. 14, no. 3, pp. 294-300, viewed 3 March 2013, via Wiley Online.

Hallan, S.I., Matsushita, K., Sang, Y. & et al. 2012, 'Age and association of kidney measures with mortality and end-stage renal disease', *JAMA*, vol. 308, no. 22, pp. 2349-2360, viewed 28 September 2014, via Jama Network.

Hammersley, M. 2007, 'The issue of quality in qualitative research', *International Journal of Research & Method in Education*, vol. 30, no. 3, pp. 287-305, viewed 26 April 2013, via Taylor Francis Online.

Hansen, E.C. 2006, *Successful qualitative health research : a practical introduction* Sydney: Allen & Unwin.

Harris, P., Nagy, S. & Vardaxis, N.J. 2005, *Mosby's dictionary of medicine, nursing & health professions*: Marrickville, N.S.W. : Elsevier-Mosby, 2006.  
1st Australian & New Zealand ed.

Hawthorne, G., Osborne, R.H., Taylor, A. & Sansoni, J. 2007, 'The SF36 Version 2: Critical analyses of population weights, scoring algorithms and population norms', *Quality of life research*, vol. 16, no. 4, pp. 661-673, viewed 2 April 2016, via JSTOR Journals.

Hoffmann, T., Bennett, S. & Del Mar, C. (eds) 2010, *Evidence-based practice across the health professions*, 1st edn, Churchill Livingstone Elsevier, London.

Howe, T.R. 2012, *Marriages & families in the 21st century. A bioecological approach*, West Sussex, UK: Wiley-Blackwell.

Jack, S. 2006, 'Utility of qualitative research findings in evidence-based public health practice', *Public Health Nursing*, vol. 23, no. 3, pp. 277-283, viewed 23 January 2013, via Wiley Online.

Jansen, D.L., Heijmans, M.J.W.M., Rijken, M., Spreeuwenberg, P., Grootendorst, D.C., Dekker, F.W., Boeschoten, E.W., Kaptein, A.A. & Groenewegen, P.P. 2013, 'Illness perceptions and treatment perceptions of patients with chronic kidney disease: Different phases, different perceptions?', *British Journal of Health Psychology*, vol. 18, no. 2, pp. 244-262, viewed 18 March 2014, via Wiley Online.

Jennings, W., Brown, R., Blebea, J., Taubman, K. & Messiner, R. 2013, 'Prevention of vascular access hand ischemia using the axillary artery as inflow', *Journal of Vascular Surgery*, vol. 58, no. 5, pp. 1305-1309, viewed 7 November 2013, via ScienceDirect.

Jennings, W., Landis, L., Taubman, K. & Parker, D. 2011, 'Clinical research study: Creating functional autogenous vascular access in older patients', *Journal of Vascular Surgery*, vol. 53, no. 3, pp. 713-719, viewed 1 April 2014, via Science Direct.

Johansen, K.L., Delgado, C., Bao, Y. & Tamura, M.K. 2013, 'Frailty and dialysis initiation', *Seminars in Dialysis*, vol. 26, no. 6, pp. 690-696, viewed 4 September 2013, via Wiley.

Jones, C. & Lyons, C. 2004, 'Case study: design? method? or comprehensive strategy?', *Nurse Researcher*, vol. 11, no. 3, pp. 70-76, via ProQuest

Josland, E., Brennan, F., Anastasiou, A. & Brown, M. 2012, 'Developing and sustaining a renal supportive care service for people with end-stage kidney disease', *Renal Society of Australasia Journal*, vol. 8, no. 1, pp. 12-18, viewed 8 April 2012, via CINAHL.

Kastrouni, M., Sarantopoulou, E., Aperis, G. & Alivanis, P. 2010, 'Quality of life of greek patients with end stage renal disease undergoing haemodialysis', *Journal of Renal Care*, vol. 36, no. 3, pp. 126-132, viewed 28 October 2012, via CINAHL.

Key, S.M. 2008, 'Optimizing dialysis modality choices around the world: a review of literature concerning the role of enhanced early pre-ESRD education in choice of renal replacement therapy modality', *Nephrology Nursing Journal*, vol. 35, no. 4, pp. 387-395, viewed 26 June 2011, via CINAHL.

Keyzer, D. 2000, 'Nursing research in practice: the case study revisited', *Australian Journal of Rural Health*, vol. 8, no. 5, pp. 266-270, viewed 29 January 2013, via Wiley Online.

Kobayashi, K., Hayakawa, A. & Hohashi, N. 2015, 'Interrelations Between Siblings and Parents in Families Living With Children With Cancer', *Journal of Family Nursing*, vol. 21, no. 1, pp. 119-148, viewed 12 March 2015, via Sage Journals.

Koncicki, H.M., Brennan, F., Vinen, K. & Davison, S.N. 2015, 'An approach to pain management in end stage renal disease: Considerations for general management and intradialytic symptoms', *Seminars in Dialysis*, vol. 28, no. 4, pp. 384-391, viewed 7 December 2015, via Wiley Online.

Koutra, K., Roumeliotaki, T., Lionis, C., Vgontzas, A.N. & Triliva, S. 2013, 'Cross-Cultural adaptation and validation of the greek version of the family adaptability and cohesion evaluation scales IV package (FACES IV Package)', *Journal of Family Issues*, vol. 34, no. 12, pp. 1647-1672, viewed 28 November 2015, via Sage Journals.

Kring, D.L. 2008, 'Using the revised Wilson and Cleary model to explore factors affecting quality of life in persons on hemodialysis', Doctor of Philosophy thesis, The University of North Carolina at Greensboro, viewed 1 July 2012, via ProQuest.

Legendre, P. 2010, 'Coefficient of concordance', in *N J Salkind (Ed), Encyclopedia of research design. [electronic resource]*, SAGE Publications, Thousand Oaks.

Lerner, R. 2005, *Making human beings human : bioecological perspectives on human development*, 'Forward', in U Bronfenbrenner edn, Thousand Oaks: Sage.

Lopez-Vargas, P.A., Craig, J.C., Gallagher, M.P., Walker, R.G., Snelling, P.L., Pedagogos, E., Gray, N.A., Divi, M.D., Gillies, A.H., Suranyi, M.G., Thein, H., McDonald, S.P., Russell, C. & Polkinghorne, K.R. 2011, 'Barriers to timely arteriovenous fistula creation: A study of providers and patients', *American Journal of Kidney Diseases*, vol. 57, no. 6, pp. 873-882, viewed 1 March 2013, via Science Direct.

MacPhail, A., Ibrahim, J.E., Fetherstonhaugh, D. & Levidiotis, V. 2015, 'The overuse, underuse, and misuse of dialysis in ESKD patients with dementia', *Seminars in Dialysis*, vol. 28, no. 4, pp. 1-7, viewed 18 July 2015, via MEDLINE.

Madhan, K. 2010, 'Quality of life', *Nephrology*, vol. 15, no. Supplement s1, pp. S32-S34, viewed 20 August 2012, via Wiley Online.

Maruish, M. 2011, *User's manual for the SF-36v2® Health Survey*, 2 edn, USA: Optum.

McGloin, S. 2008, 'The trustworthiness of case study methodology', *Nurse Researcher*, vol. 16, no. 1, pp. 45-55, viewed 16 December 2012, via ProQuest

Melnik, B.M., Gallagher-Ford, L., Long, L.E. & Fineout-Overholt, E. 2014, 'The establishment of evidence-based practice competencies for practicing registered nurses and advanced practice nurses in real-world clinical settings: Proficiencies to improve healthcare quality, reliability, patient outcomes, and costs', *Worldviews on Evidence-Based Nursing*, vol. 11, no. 1, pp. 5-15, viewed 21 October 2014, via CINAHL.

Mendelssohn, D. & Benaroya, B. 2008, 'The modern haemodialysis factory: must quality improvement trump personalized care', *Nephrology Dialysis Transplant*, vol. 23, no. 3, pp. 786-788, viewed 7 August 2011, via Oxford Journals.

Mertens, D.M. 2012, 'What comes first? the paradigm or the approach?', *Journal of Mixed Methods Research*, vol. 6, no. 4, pp. 255-257, viewed 14 May 2013, via SAGE Journals.

Mertens, D.M. & Hesse-Biber, S. 2012, 'Triangulation and mixed methods research: provocative positions', *Journal of Mixed Methods Research*, vol. 6, no. 2, pp. 75-79, viewed 5 May 2013, via SAGE Journals.

Meyers, L., Gamst, G. & Guarino, A. 2006, *Applied multivariate research: Design and interpretation*, Thousand Oaks: Sage.

Mitrou, G.I., Grigoriou, S.S., Konstantopoulou, E., Theofilou, P., Giannaki, C.D., Stefanidis, I., Karatzaferi, C. & Sakkas, G.K. 2013, 'Exercise training and depression

in ESRD: A review', *Seminars in Dialysis*, vol. 26, no. 5, pp. 604-613, viewed 26 October 2013, via Wiley Online.

Moist, L. 2014, 'What are the causes of the ill effects of chronic hemodialysis?', *Seminars in Dialysis*, vol. 27, no. 1, pp. 23-25, viewed 27 February 2014, via Wiley Online.

Moist, L., Bragg-Gresham, J., Pisoni, R., Saran, R., Akiba, T., Jacobson, S., Fukuhara, S., Mapes, D., Rayner, H., Saito, A. & Port, F. 2008, 'Travel time to dialysis as a predictor of health-related quality of life, adherence, and mortality: The dialysis outcomes and practice patterns study (DOPPS)', *American Journal of Kidney Diseases*, vol. 51, no. 4, pp. 641-650, viewed 3 March 2013, via ScienceDirect.

Moist, L., Lok, C., Vachharajani, T., Xi, W., AlJaishi, A., Polkinghorne, K., Vazquez, M. & Lee, T. 2012, 'Optimal hemodialysis vascular access in the elderly patient', *Seminars in Dialysis*, vol. 25, no. 6, pp. 640-648, viewed 24 November 2012, via Wiley Online.

Moist, L.M., Lee, T.C., Lok, C.E., Al-Jaishi, A., Xi, W., Campbell, V., Graham, J., Wilson, B. & Vachharajani, T.J. 2013, 'Education in vascular access', *Seminars in Dialysis*, vol. 26, no. 2, pp. 148-153, viewed 6 April 2014, via Scopus.

Morris, B., Shakespeare-Finch, J. & Scott, J. 2007, 'Coping processes and dimensions of posttraumatic growth', *The Australasian Journal of Disaster and Trauma Studies*, vol. 2007, no. 1, viewed 27 March 2015, via Massey University, University of New Zealand.

Morris, S.B., Huang, J., Zhao, L., Sergeant, J.D. & Neuhengen, J. 2014, 'Measurement equivalence of the empowerment scale for white and black persons with severe mental illness', *Psychiatric Rehabilitation Journal*, vol. 37, no. 4, pp. 277-283, viewed 26 November 2013, via ProQuest.

Morse, J. 2015, 'Critical analysis of strategies for determining rigor in qualitative inquiry', *Qualitative Health Research*, vol. 25, no. 9, pp. 1212-1222, viewed 9 December 2015, via Sage Journals.

Muringai, T., Noble, H., McGowan, A. & Chamney, M. 2008, 'Dialysis access and the impact on body image: role of the nephrology nurse', *British Journal of Nursing*, vol. 17, no. 6, p. 362, viewed 5 September 2013, via ProQuest.

Naik, N., Hess, R. & Unruh, M. 2012, 'Measurement of health-related quality of life in the care of patients with ESRD: Isn't this the metric that matters?', *Seminars in Dialysis*, vol. 25, no. 4, pp. 439-444, viewed 24 November 2012, via Wiley Online.



National Kidney Foundation 2006, 'Clinical practice guidelines for vascular access', *American Journal of Kidney Diseases*, vol. 48, no. Supplement 1, pp. S176-S247, viewed 11 February 2011, via ScienceDirect.

Ng'ang'a, N., Byrne, M.W. & Ngo, T.A. 2014, 'In their own words: The experience of professional nurses in a northern vietnamese women's hospital', *Contemporary Nurse: A Journal for the Australian Nursing Profession*, vol. 47, no. 1/2, pp. 168-179, viewed 14 November 2015, via Informit.

Noor, K. 2008, 'Case study: A strategic research methodology', *American Journal of Applied Sciences*, vol. 5, no. 11, pp. 1602-1604, viewed 16 December 2012, via Science Publications.

Olson, D., Gorall, D. & Tiesal, J. 2006, *FACES IV: Development and validation*, Minnesota: Life Innovations.

Olson, D. & Wilson, M. 1982, "Family satisfaction", in D Olson, HI McCubbin, H Barnes, A Larsen, M Muxen & M Wilson (eds), *Family inventories: Inventories used in a national survey of families across the family life cycle*, University of Minnesota, St Paul.

Pagels, A.A., Söderquist, B.K. & Heiwe, S. 2015, 'Differences in illness representations in patients with chronic kidney disease', *Journal of Renal Care*, vol. 41, no. 3, pp. 146-155, viewed 12 November 2015, via Wiley Online.

Paraskevas, K., Bessias, N., Koupidis, S., Tziviskou, E., Mikhailidis, D. & Oreopoulos, D. 2010, 'Incidence of end-stage renal disease in the elderly: a steadily rising global socioeconomic epidemic', *International urology and nephrology*, vol. 42, no. 2, pp. 523-525, viewed 27 February 2013, via Springer Link.

Parry, R., Land, V. & Seymour, J. 2014, 'How to communicate with patients about future illness progression and end of life: A systematic review', *BMJ Supportive and Palliative Care*, vol. 4, no. 4, pp. 331-341, viewed 2 February 2015, via Scopus.

Polkinghorne, K. 2013, 'Vascular access surveillance: Time to end the controversy', *Seminars in Dialysis*, vol. 26, no. 3, pp. 257-259, viewed 25 August 2013, via Wiley Online.

Polkinghorne, K., Chin, G., MacGinley, R., Owen, A., Russell, C., Talaulikar, G., Vale, E. & Lopez-Vargas, P. 2013, 'KHA-CARI Guideline: Vascular access – central venous catheters, arteriovenous fistulae and arteriovenous grafts', *Nephrology*, vol. 18, no. 11, pp. 701-705, viewed 25 October 2013, via Wiley Online.

Polkinghorne, K., Seneviratne, M. & Kerr, P.G. 2009, 'Effect of a vascular access nurse coordinator to reduce central venous catheter use in incident hemodialysis

patients: A quality improvement report', *American Journal of Kidney Diseases*, vol. 53, no. 1, pp. 99-106, viewed 12 July 2011, via Science Direct.

Porter, E., Watson, D. & Bargman, J.M. 2013, 'Education for patients With progressive CKD and acute-start dialysis', *Advances in Chronic Kidney Disease*, vol. 20, no. 4, pp. 302-310, viewed 27 September 2013, via Science Direct.

Quinn, R.E. & Rohrbaugh, J. 1983, 'A spatial model of effectiveness criteria. Toward a competing values approach to organizational analysis', *Management Science*, vol. 29, no. 3, pp. 363-377, viewed 12 April 2014, via STOR.

Radley, A. & Chamberlain, K. 2012, 'The Study of the case: conceptualising case study research', *Journal of Community & Applied Social Psychology*, vol. 22, no. 5, pp. 390-399, viewed 5 January 2013, via WileyOnline.

Richard, C.J. & Engebretson, J. 2010, 'Negotiating living with an arteriovenous fistula for hemodialysis', *Nephrology Nursing Journal*, vol. 37, no. 4, pp. 363-374; quiz 375, viewed 10 September 2010, via ProQuest

Ronco, C. & Levin, N.W. 2004, *Hemodialysis vascular access and peritoneal dialysis access*, vol. 142, Contributions to Nephrology, Levin N.W. (New York, N.Y.) Karger.

Rosa, E.M. & Tudge, J. 2013, 'Urie Bronfenbrenner's theory of human development: Its evolution from ecology to bioecology', *Journal of Family Theory & Review*, vol. 5, no. 4, pp. 243-258, viewed 23 July 2014, via Wiley Online.

Salkind, N. 2010, 'Spearman rank order correlation', in *N J Salkind (Ed), Encyclopedia of research design. [electronic resource]*, SAGE Publications, Thousand Oaks.

Sandelowski, M. 1996, 'One is the liveliest number: The case orientation of qualitative research', *Research in Nursing & Health*, vol. 19, no. 6, pp. 525-529, viewed 21 April 2013, via Wiley Online.

Sandelowski, M. 2011, 'Casing: the research case study', *Research in Nursing & Health*, vol. 34, no. 2, pp. 153-159, viewed 5 January 2013, via Wiley Online.

Saxena, M. & Adamsons, K. 2013, 'Siblings of individuals with disabilities: Reframing the literature through a bioecological lens', *Journal of Family Theory & Review*, vol. 5, no. 4, p. 300, viewed 2 December 2013, via CINAHL.

Scerra, N. 2012, 'Strengths-based practices: An overview of the evidence', *Developing Practice: The Child, Youth and Family Work Journal*, no. 31, p. 43, viewed 26 June 2015, via Informit.

Schmidt, R., Goldman, R. & Germain, M. 2012, 'Pursuing permanent hemodialysis vascular access in patients with a poor prognosis: Juxtaposing potential benefit and harm', *American Journal of Kidney Diseases*, vol. 60, no. 6, pp. 1023-1031, viewed 21 January 2013, via ScienceDirect.

Schneider, Z., Whitehead, D. & Elliot, D. 2008, *Nursing & midwifery research*, 3rd edn: Mosby Elsevier.

Sgroi, M.D., Patel, M.S., Wilson, S.E., Jennings, W.C., Blebea, J. & Huber, T.S. 2013, 'Debate: The optimal initial choice for permanent arteriovenous hemodialysis access', *Journal of Vascular Surgery*, vol. 58, no. 2, pp. 539-548, viewed 19 February 2014, via ScienceDirect.

Sharp, J., Mobley, C., Hammond, C., Withington, C., Drew, S., Stringfield, S. & Stipanovic, N. 2012, 'A mixed methods sampling methodology for a multisite case study', *Journal of Mixed Methods Research*, vol. 6, no. 1, pp. 34-54, viewed 15 December 2012, via SAGE Journals.

Smith, L. 2011a, 'Applying the Bioecological Theory of Human Development to learning: Enhancing student engagement in online learning.', paper presented to University of Tasmania. 10th Annual Teaching Matters Conference 2011, Hobart, Tasmania,  
<[http://www.utas.edu.au/\\_\\_data/assets/pdf\\_file/0004/309370/TM11\\_Smith.pdf](http://www.utas.edu.au/__data/assets/pdf_file/0004/309370/TM11_Smith.pdf)>.

Smith, L. 2011b, 'Spiritual wellbeing and its relationship to adolescent resilience. A case study of Australian youth attending one local church.', Doctor of Philosophy thesis, Australian Catholic University.

Smith, L., Webber, R. & DeFrain, J. 2013, 'Spiritual well-being and its relationship to resilience in young people: A mixed methods case study', *SAGE Open*, vol. 3, no. 2, pp. 1-16, viewed 16 February 2014, via Sage Open.

Smith, N. 1990, 'The case study: a useful research method for information management', *Journal of Information Technology*, vol. 5, no. 3, pp. 123-133, viewed 14 April 2013, via ProQuest.

Sood, M.M., Akbari, A., Hiebert, B., Hiremath, S., Komenda, P., Rigatto, C., Zimmerman, D. & Tangri, N. 2015, 'Trends in arteriovenous fistula use at dialysis initiation after automated eGFR reporting', *Seminars in Dialysis*, vol. 28, no. 4, pp. 439-445.

Stake, R.E. 2005, *Multiple Case Study Analysis*, Guilford Publications, New York,  
<<http://UTAS.ebib.com.au/patron/FullRecord.aspx?p=362572>>.

Swinnen, J. 2011, 'Duplex ultrasound scanning of the autogenous arterio venous hemodialysis fistula: a vascular surgeon's perspective', *Australian Journal of Ultrasound in Medicine*, vol. 14, no. 1, pp. 17-23, viewed 30 September 2012, via Minnis Journals.

Tashakkori, A. & Teddlie, C. 2010, 'Putting the human back in "human research methodology": the researcher in mixed methods research', *Journal of Mixed Methods Research*, vol. 4, no. 4, pp. 271-277, viewed 13 December 2012, via SAGE Journals.

Theofilou, P. 2011, 'Noncompliance with medical regimen in haemodialysis treatment: A case study', *Case Reports in Nephrology*, vol. 2011, no. N/a, pp. 1-4, viewed 3 December 2012, via Hindawi

Thomas, D.J. 2006, 'Case study as a method of research', in *Encyclopedia of nursing research*, Springer Publishing Company, New York, United States, New York, pp. 61-63, R30, via ProQuest.

Tims, S., King, L. & Bennett, P. 2007, 'Empowerment for people with end stage renal disease: a literature review', *Renal Society of Australia Journal*, vol. 3, no. 2, pp. 52-58, viewed 29 July 2011, via Flinders Academic Commons.

Tobin, R. 2010, 'Descriptive case study', in A Mills, G Durepos & E Wiebe (eds), *Encyclopaedia of case study research*, Sage, Los Angeles, vol. 1, pp. 288-289.

Tong, A., Cheung, K.L., Nair, S.S., Kurella Tamura, M., Craig, J.C. & Winkelmayer, W.C. 2014, 'Thematic synthesis of qualitative studies on patient and caregiver perspectives on end-of-life Care in CKD', *American Journal of Kidney Diseases*, vol. 63, no. 6, pp. 913-927, viewed 18 June 2014, via CINAHL.

Tordoir, J., Canaud, B., Haage, P., Konner, K., Basci, A., Fouque, D., Kooman, J., Martin-Malo, A., Pedrini, L., Pizzarelli, F., Tattersall, J., Vennegoor, M., Wanner, C., ter Wee, P. & Vanholder, R. 2007, 'EBPG on vascular access', *Nephrology Dialysis Transplantation*, vol. 22, no. Supplement 2, pp. ii88-ii117, viewed 2 June 2010, via Oxford Journals

Torraco, R.J. 2005, 'Writing Integrative Literature Reviews: Guidelines and Examples', *Human Resource Development Review*, vol. 4, no. 3, pp. 356-367, viewed 12 March 2013, via ERIC.

Torrance, H. 2012, 'Triangulation, respondent validation, and democratic participation in mixed methods research', *Journal of Mixed Methods Research*, vol. 6, no. 2, pp. 111-123, viewed 11 May 2013, via SAGE Journals.

Tudge, J.R.H., Mokrova, I., Hatfield, B.E. & Karnik, R.B. 2009, 'Uses and misuses of Bronfenbrenner's bioecological theory of human development', *Journal of Family*

*Theory and Review*, vol. 1, no. 4, pp. 198-210, viewed 15 April 2014, via Wiley Online Library.

Underhill, A.T., LoBello, S.G. & Fine, P.R. 2004, 'Reliability and validity of the family satisfaction scale with survivors of traumatic brain injury', *Journal of Rehabilitation Research & Development*, vol. 41, no. 4, pp. 603-609, viewed 10 January 2015, via CINAHL.

van der Veer, S., Jager, K., Nache, A., Richardson, D., Hegarty, J., Couchoud, C., De Keizer, N. & Tomson, C. 2011, 'Translating knowledge on best practice into improving quality of RRT care: a systematic review of implementation strategies', *Kidney International*, vol. 80, no. 10, pp. 1021-1034, viewed 17 November 2012, via ProQuest Health & Medical Complete.

Van Loon, M.M., Kessels, A.G.H., Van Der Sande, F.M. & Tordoir, J.H.M. 2009, 'Cannulation and vascular access-related complications in hemodialysis: Factors determining successful cannulation', *Hemodialysis International*, vol. 13, no. 4, pp. 498-504, viewed 10 July 2010, via Wiley Online.

Wang, N., Yang, J., Yu, X., Hu, J., Xing, C., Ju, X., Shen, X.I.A., Qian, J.U.N., Zhao, X. & Wang, X. 2008, 'Radial artery calcification in end-stage renal disease patients is associated with deposition of osteopontin and diminished expression of  $\alpha$ -smooth muscle actin', *Nephrology*, vol. 13, no. 5, pp. 367-375, viewed 9 September 2013, via Wiley Online.

Ware, J.E., Jr, Kosinski, M., Bjorner, J.B., Turner-Bowker, D.M., Gandek, B. & Maruish, M.E. 2008, *SF-36v2® Health survey: Administration guide for clinica trial investigators*, Lincon, RI: Quality Metric Incorporated.

Washington, T.R. 2013, 'Older adult kidney disease self-management behaviors and their relationship to depression, self-efficacy, illness perceptions, and social support', 3594236 thesis, The University of North Carolina at Chapel Hill, via ProQuest Dissertations & Theses A&I.

Weisner, T.S. 2008, 'The Urie Bronfenbrenner Top 19: Looking Back at His Bioecological Perspective', *Mind, Culture & Activity*, vol. 15, no. 3, pp. 258-262, viewed 14 March 2015, via Taylor & Francis Online.

White, A., Wong, W., Sureshkumur, P. & Singh, G. 2010, 'The burden of kidney disease in Indigenous children of Australia and New Zealand, epidemiology, antecedent factors and progression to chronic kidney disease', *Journal of Paediatrics and Child Health*, vol. 46, no. 9, pp. 504-509.

Whittemore, R. & Knafl, K. 2005, 'The integrative review: updated methodology', *Journal of Advanced Nursing*, vol. 52, no. 5, pp. 546-553 548p.

Wilson, B., Harwood, L., Oudshoorn, A. & Thompson, B. 2010, 'The culture of vascular access cannulation among nurses in a chronic hemodialysis unit', *CANNT Journal*, vol. 20, no. 3, pp. 35-42, viewed 2 March 2011, via ProQuest.

World Health Organisation (WHOQOL) 1997, *WHOQOL Measuring quality of life*, <[http://www.who.int/mental\\_health/media/68.pdf](http://www.who.int/mental_health/media/68.pdf)>.

Yin, R.K. 2009, *Case study research design and methods*, Fourth Edition edn, London: Sage.

Zalai, D., Szeifert, L. & Novak, M. 2012, 'Psychological distress and depression in patients with chronic kidney disease', *Seminars in Dialysis*, vol. 25, no. 4, pp. 428-438, viewed 24 November 2012, via Wiley Online.

# APPENDICES

## Appendix 1...*The bioecological model*

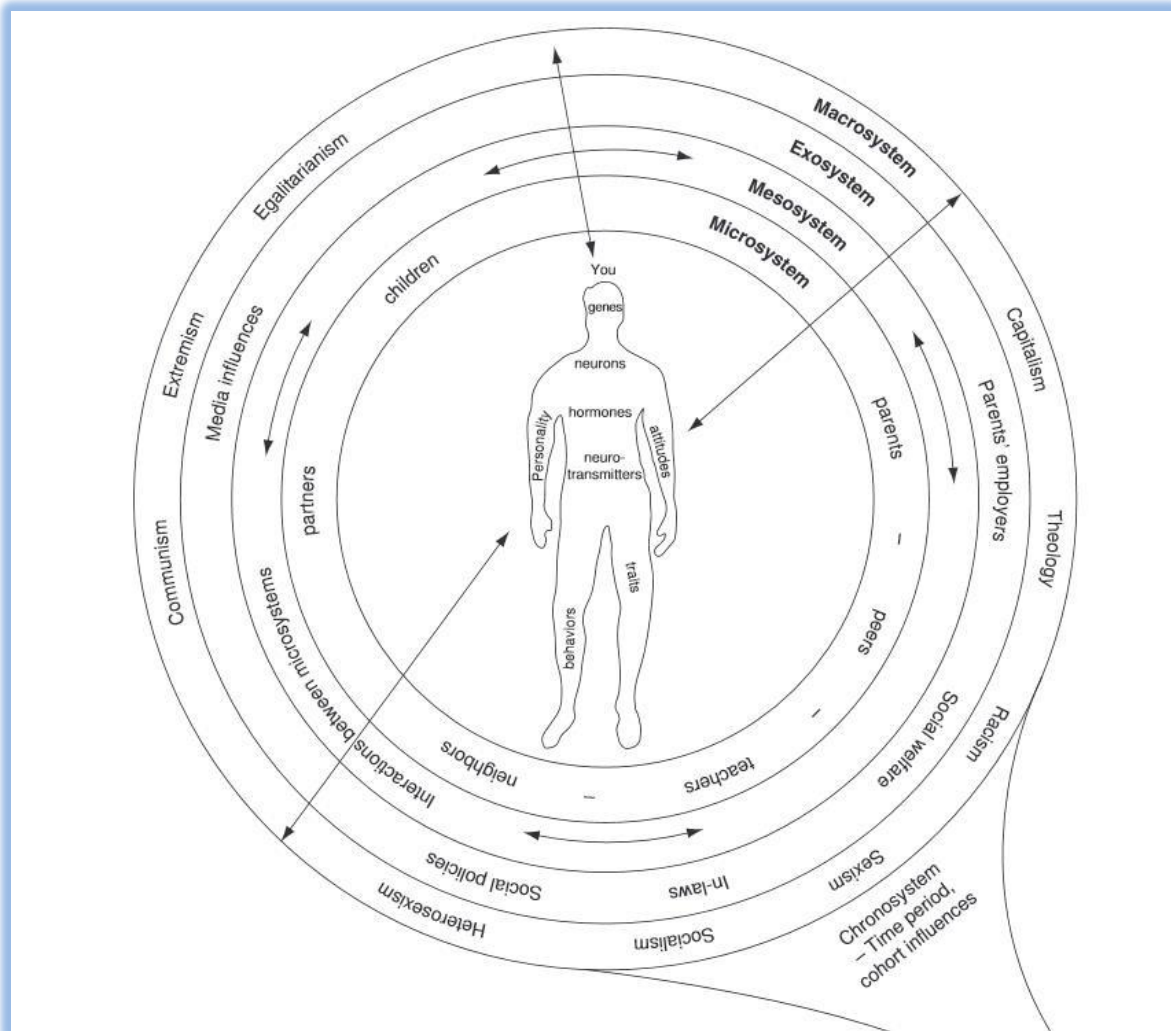


Diagram. Appendix 1...*The bioecological model* (Howe 2011)

## ***Appendix 2...Understanding the journey travelled by patients and carers living with end stage kidney disease and haemodialysis***

### **Introduction**

In brief, the following paper was submitted to the Australia Nursing and Midwifery Journal (ANMJ) as my emic perspective. I reflect on my own experiences of caring for patients and their family and friends as carers of their life-journeys in regard to living with CKD-ESKD. I have supported this story with the available literature. This paper adds to the forming of the descriptive theory for this CS, as the utility of a CS strategy is in 'the articulation of what is already known about the phenomenon, called descriptive theory' (Tobin 2010, p. 288).

Understanding the journey travelled by patients and carers living with end stage kidney disease and haemodialysis has been published in the Australian Nursing and Midwifery Journal March 2016, vol. 23, no. 8, pp. 26-29.



This article has been removed for  
copyright or proprietary reasons.

Cowan, D., 2016, Understanding the journey travelled by patients and carers living with end stage kidney disease and haemodialysis, Australian nursing and midwifery journal, 23(8), 26-29

## Appendix 3... Narrative literature review protocol

Chapter Three presents the publication of the narrative literature review completed as part of the descriptive theory of this case study. The narrative literature review results are included in the case study as a source of data in line with the conventions of case study methodology (Tobin 2010). The narrative literature review protocol was developed based on qualitative systematic and narrative review approaches completed on mature topics, as presented in the article. Further to the details included in the published article, this Appendix 3 will articulate the expanded research protocol and adapted 'PRISMA Diagram' Appendix 3.1 for the narrative literature review.

### AIM

The aim of this narrative literature review (1997 to March 2014) was to explore the factors that influence the care of a patient's VA for haemodialysis.

### Sources of literature

A comprehensive search of databases and websites was undertaken. This included:

Societies and Data-Bases Searched	
Societies	
Australia and New Zealand Dialysis and Transplant Registry (ANZDATA)	
European Renal Association-European Renal Best Practice (ERA-ERBP)	
Kidney Disease Improving Global Outcomes (KDIGO)	

Kidney Health Australia - Caring for Australasians with Renal Impairment (KHA-CARI)
National Institute for Health and Care Excellence (NICE)
Renal Society of Australasia (RSA)
The Dialysis Outcomes Practice Patterns Study (DOPPS)
The National Kidney Foundation Kidney Disease Outcomes Quality Initiative (NKF KDOQI)
<i>United States Renal Data System (USRDS)</i>
The Cochrane Collaboration
<b>Data Bases</b>
Biomed Central. The open access publisher. (BMC)
Clinicaltrials.gov A service of the U.S. National Institutes of Health
Cumulative Index to Nursing and Allied Health Literature (CINAHL)
Flinders Academic Commons
Informit
Minnis Journals
Oxford Journals
ProQuest
Renal Association (UK)
Sage Journals
ScienceDirect
The Joanna Briggs Institute (JBI)
Wiley Publishing, Wiley Online and Wiley-Blackwell

*Table Appendix3.1: Sources of literature*

### **Outline of the inclusion and exclusion criteria**

- A wide inclusion approach retained to aid in capturing the breadth of literature related to the stated aim.
- Following initial large number of items identified for potential inclusion, each abstract was reviewed to determine the quality of the original research and publication.
- The Bioecological Theory of Human Development (person, process, context and time) informed the literature search, data extraction and the thematic analysis of the literature (the data) providing the key factors to explore.
- Evaluation of the reported methodology and level of evidence of each item was undertaken. Publications that did not specify a research method or the protocol of synthesis of published literature were excluded.
- Diverse research methodologies (both experimental and nonexperimental research) included.
- Two standards of VA management protocols included—evidence based clinical practice guidelines (CPGs) and clinical practice recommendations (CPRs).
- 35 articles including three VA management guidelines were retained for inclusion in the narrative review.

- The Bioecological Theory of Human Development (person, process, context and time) guided the data extraction process.
- From the data extracted for the thematic analysis of the data (see Table 3.2 'Characteristics of systematic reviews and narrative reviews compared' utilising the process outlined by Braun & Clarke 2006, see p. 96, was undertaken).

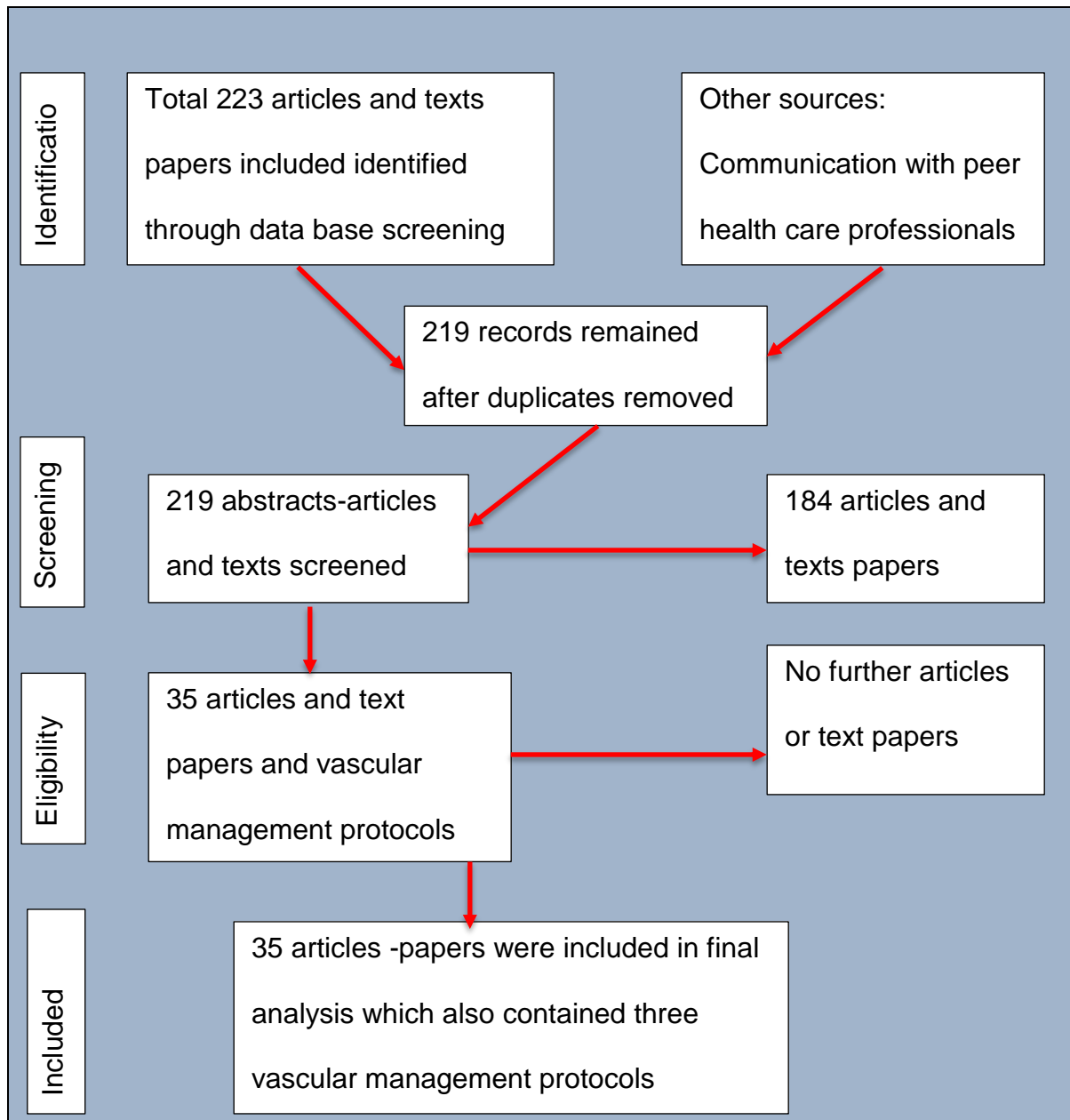


Diagram. Appendix 3.1... PRISMA Diagram

## **Appendix 4...*Publications and presentations during candidature***

### ***Publications***

#### ***Journal of Renal Care***

***Title:*** *Care of a patient's vascular access for haemodialysis: A narrative literature review.*

#### ***Significance of Journal of Renal Care***

The Journal of Renal Care (JORC) is the official publication of the European Dialysis and Transplant Association/European Renal Care Association (EDTNA/ERCA). The JORC publishes a broad selection of peer-reviewed clinical, research and educational articles for health care professionals involved in the care of people living with kidney disease. The JORC provides relevant content which is up to date and reflective of the diversity and complexity of growing renal populations. The JORC mission is to “Achieve the best standard of treatment and support for patients and their families around the world” and a vision to “Provide continuing education in renal care and become the most recognized multi-disciplinary renal care organization in the world.”

#### ***Journal of Renal Care reviewers' comments about this article:***

##### ***Reviewer one:***

This literature-review is important and should now be published. The author identified five themes and only with this knowledge is a holistic view of care possible.

##### ***Reviewer two:***

The paper reads much better now and the authors have made the changes recommended by the reviewers. I am happy to recommend the paper for publication.

## **Clinical Case Reports**

**Title:** *Maintaining a viable vascular access for haemodialysis in an elderly person with diabetes: A journey to live, not just to stay alive.*

### **Significance of the Clinical Case Reports**

The Clinical Case Reports (CCR) is a peer reviewed journal which is supported by a number of societies published by Wiley. The CCR promotes healthcare outcomes with 'Our vision is to improve global health and increase clinical understanding' having an aim and scope to improve global health and increase clinical understanding using case reports relating to individuals in order to convey information, that is important to best practice. The CCR journal has a mission 'to use clinical case histories to disseminate best practice, to examine important common as well as uncommon clinical scenarios, and to illustrate and inform the use of important clinical practice guidelines and systematic reviews. In achieving this we will be the most influential global open case report.'

## **Australian Nursing and Midwifery Journal**

**Title:** *Understanding the journey travelled by patients and carers living with end stage kidney disease and haemodialysis*

### **Significance of the Nursing and Midwifery Journal**

The Australian Nursing and Midwifery Journal (ANMJ) is a journal for all Australian nurses and midwives, distributed to more than 98,750 nurses around Australia. The ANMJ offers news, features and analysis to keep nurses and midwives well informed.



The journal includes clinical updates on best practice “how to guide” for nurses in an area of nursing practice relevant to a wide cross section of nurses.

### ***Presentations***

#### ***2012: UTAS School of Nursing and Midwifery Symposium.***

Presentation and Abstract. Title of presentation: “Case Study: Vascular access management for patients requiring haemodialysis in a satellite haemodialysis unit clinical setting”. This topic forms content in this dissertation.

#### ***2012: University of Tasmania. Graduate Research Conference, 2012. Sharing Excellence in Research (SEiR)***

Poster, abstract and defence: Taking Care of a Lifeline. This topic forms content in Chapter three.

#### ***2013: RSA Annual Conference***

Poster, abstract and defence “Vascular Access: Enhancing the Care of a “Life-Line”. The Journey Begins” (abstract no: 90.00). This topic forms content in Chapter two and Chapter three.

#### ***2013: Royal North Shore Hospital Sydney. VA Advanced Care Workshop for Dialysis Access***

Q & A Panel: Patients’ VA care. This topic forms content within this dissertation Chapter two and Chapter three.

#### ***2013: RSA NSW Annual Workshop***

Presentation and abstract ‘Vascular Access: The Care of a “Life-Line” is Complicated: Just ask the patient’. This topic presented the findings of the narrative review of which the content forms Chapter three.

***2014: Royal North Shore Hospital, Sydney. VA Advanced Care Workshop for  
Dialysis Access***

Presentation 'The future of nephrology education is changing'. This presented the changing face and the need for empowerment through education using advanced methods and mediums in relation to eLearning education to advance the care of patients' VAs.

***2015: August RSA NSW/ACT Branch Education Evening & General Meeting***

Presenter: Debi Cowan – "It's never too late" including Web-conference availability. This topic presents the higher degree journey and my dissertation including the research project (experiences of my HDR journey). The RSA NSW/ACT had invited me to present my journey to encourage other nephrology-renal nursing peers to complete an MN, research for informing EBP.

**Appendix 5...Table S1 Comparison and critical review of the literature included in the narrative review**

<b>Table S1 Comparison and critical review of the literature included in the narrative review</b>						
<b>Literature Source</b>	<b>Aim &amp;/or Phenomenon of interest</b>	<b>Type of Study &amp; Research Design</b>	<b>Participants &amp; region of study</b>	<b>Main Findings &amp; Outcomes</b>	<b>Strengths, Weaknesses &amp;/or Limitations</b>	<b>Further comments</b>
<b>Aason et al. 2012</b>	Nurse's perception of patients 75yrs & older participation when receiving care in haemodialysis units (HDU) & that of their next of kin. Including participation in patient end-of -life decisions.	Interviews & Critical discourse analysis.	Norway. Participant: N=10. Nurses Working in the clinical environment of a HDU.	Three discursive practices found: 1. The nurse's power & control. 2. Sharing power with patient. 3. Transferring power to next of kin. Nurse's responses generally relied on biomedical explanation & ethical principal to add beneficence when justifying their actions.	Strengths: The interviewer's prior work in HDU environments could have influenced the nurse's stories & hence had been both strength as well as a weakness. Weaknesses: Small sample size of participants. Single centre study.	Future research: Examine social practice in HDUs while incorporating holistic care that embraces both patient & next of kin participation in patient care, treatment & end-of-life decisions.

<b>Abdelhafiz et al. 2013</b>	Focus on continual rise of aging populations. Associated to increase risk of chronic diseases, CKD, ESKD & co-morbidities.	Literature review	UK	Prevalence stage 3 CKD increases with age. Structural & functional changes of kidneys are related to age causing decline in GFR onto CKD. Competing risks of co-morbidities in patients with CKD results in the majority of older patients not progressing to ESKD due to mortality. CKD in older people is associated with geriatric syndromes that lead to increased disability & frailty. Management is complex & needs to be individualized.	Strengths: Reviewers included topics such as cause, progression, slowing progression of CKD in elderly populations & future management of elderly patients with CKD.	Outcome: Individualized management focusing on patient goals is more likely to be appropriate for older people living with CKD. Goals of therapy will depend on patient choice.
<b>Ayoub et al. 2014</b>	Relationship between laboratory values & QOL of patients receiving haemodialysis (HD) therapy.	Examination of relationship between laboratory values & QOL. Surveys included: 1. Demographic elements 2. Health status 3. QOL. An aim of the	United Arab Emirates (UAE): Participants N=130 Patients receiving regular sessions of HD therapy for a period of greater than three months. Demographics: 18 years &	No significant relationship between laboratory values & questionnaires SF36 & QOL index. Positive impact: Correlation between patient laboratory results pre dialysis serum creatinine levels & responses SF-36. Negative impacts to QOL: 1. Co-morbidities 2. Major events in prior 12 months	Strengths: QOL assessment included both SF-36 & QOL Index disease specific dialysis version. Weaknesses: Small sample size, Single hospital with well-defined protocols, limited variability. Did not include factors such as type of dialyzers & blood flows, frequency of treatment,	Future research: Larger & more diverse patient sample numbers examining proxy measures to the adequacy of HD therapy, which includes addition of factors that directly or indirectly influence patient HD therapy

		study included ascertaining culturally acceptable of assessment tools. Data analysis: SPSS software & One-way ANOVA	older, Males 70.5%, Female 29.5%, Average age 49.4 years, Nationals 39.9% Expats 59.9% Around 50% had co-morbidities. Single centre HDU.	Positive impacts: 1. Length of time lived in the UAE. 2. Being fully employed 3. Knowledge about cause of disease.	The SF-36 version was chosen at that time as being the only available for Arabic as well as English speaking participants.	outcomes.
<b>Barnes et al. 2013</b>	Initiation of a nurse led program to educate HD nurses in: Shared Haemodialysis Care (SHC) with an objective to support patients receiving HD therapy in HDUs to take on aspects of their own treatment.	Assessment of nurses knowledge pre & post participation in a four-day training on SHD. 25% of nurse from each HDU, Junior, charge & staff nurses & Level 3 healthcare assistants (unqualified nurses).	UK: Participants N=not specified HDUs across Yorkshire & Humber North England & areas of healthcare.	Pre & post participant questionnaires had shown every cohort had demonstrated significant positive shifts in all objectives of the training program. 25% of nurses had been included (reached) in all HDUs but one.	Strengths: The SHC program supported change agents by adopting an approach utilizes motivational interviewing, thus a flow on effect of nursing as champions of change, cascading knowledge & competencies, empowers their peers & patients.  Limitation: Participants from 6 HDUs, from same region.	Positive approaches toward barriers /problem solving, with “can do” attitudes. Patients are both encouraged & enabled to gain their independence. Hence to self-care/manage resulting in improving patients QOL. This concept aims to empower individuals across HDU

						environments. SHC is a solid base for future qualitative & quantitative research into greater patient engagement in their HD care.
<b>Bennett 2011</b>	Aim: Explore nurse perceptions who were working in a satellite HD unit (SHDU) of quality nursing care & how aspects of power influenced quality of care.	Critical ethnography. Data collected over a 12 months period during 2005. 1. Non-participant observation. 2. Semi-structured interviews lasting 60-120 minutes. 3. Document analysis. Describing the nurse culture, while changing the culture of the nurses. Qualitative coding methods	Australia Participants: Individual consent received from each nurse who participated, and from each patient who had the potential to be observed during fieldwork. N is not recorded. Interviews n = 8. Nurses With varied years of experience i.e. 1-15 working in HDUs.	Nurses considered technical knowledge & skills along with personal respect as quality rather than tasks such as monitoring patient blood pressure long term or patient transport to & from the SHDU as priorities in maintaining quality patient care.	Limitations: 1. Small sample size. 2. Single centre study. 3. Included were the nurses, as a sub-culture of individuals within a SHDU environment. Therefore individuals within other groups were not included in the study e.g. patients, carers & healthcare professionals e.g. doctors & allied health caring for this group of patients. This may have provided greater understanding of the culture within this SHDU environment. 4. Interpretation of nurses perceptions were through one person's critical lens.	Implications for practice: 1. Patients in SHDUs can benefit from empowered nurses making decisions within their scope of practice. 2. Empowered nurses can empower patients in their care. 3. Quality care is far more complex than evaluating and responding to quantitative measures that utilize biomedical markers such as urea clearance.

		utilized those proposed by Auerback & Silverstein (2003) using NVIVO 2005 Software.	Nurses all had formal haemodialysis specialist training.			
<b>Bonner et al. 2010</b>	<p>1.Examine impact of fatigue on patient' daily living activities (DLAs) when living with CKD.</p> <p>2. Compare with pre-dialysis &amp; different renal replacement therapies (RRT).</p> <p>3. Identify whether items in the Fatigue Severity Scale (FSS) are more predictive of DLAs.</p>	<p>Descriptive cross-sectional design to assess differences in levels of activity of groups of persons with CKD defined by their renal history &amp; mode of RRT.</p> <p>Surveys:</p> <p>1. The Human Activity Profile (HAP) self-reporting survey having a specific focus on patient's DLAs.</p> <p>2. FSS is a 7 point Likert scale level of physical fatigue.</p>	<p>Australia:</p> <p>Participants N=112</p> <p>Patients one SHDU &amp; home RRT</p> <p>Female 45</p> <p>Male 67</p> <p>Mean age 55 years</p> <p>48 indigenous</p> <p>64 non-indigenous</p>	<p>Fatigue was reported as experienced by patients in stages of pre-dialysis as well as in ESKD receiving RRT.</p> <p>Patients receiving peritoneal dialysis reported experiencing higher levels of fatigue than those in pre-dialysis stages or receiving haemodialysis therapy.</p> <p>If fatigue was reported in the FSS scale patients were more likely to report lower overall DLAs.</p>	<p>Strengths:</p> <p>1. The study included patients at both pre-dialysis &amp; receiving RRTs allowing these groups of patients to share their experiences.</p> <p>2. Surveys examined patient activity &amp; level of fatigue experienced</p> <p>3. Examined variants e.g. course of CKD.</p> <p>Weaknesses:</p> <p>Singe centre study.</p> <p>HAP &amp; FSS being self-reporting surveys could lead to bias responses.</p>	<p>It is important for healthcare professionals to understand that higher levels of fatigue can be reported by all patients living with CKD regardless of whether they are in stages of pre-dialysis or receiving RRT.</p> <p>Requiring focus &amp; monitoring of patient fatigue.</p>

		3. Review patient's medical records. Data Analysis: SPSS v16 for Multifactorial analysis of variance.				
<b>Brown &amp; Harvie 2010</b>	Australian Nephrology nurse practitioners. Making a difference in nephrology healthcare.	Report	Australia	Correlations demonstrate NPs roles are effective, thus far revealing reductions in patient hospital admission rates. Enhancing management of anaemia & bone disease has improved so has patient satisfaction. Nephrology NPs are working with universities to engage in education of undergraduates & partake in research projects, as components of their roles.	Strengths: Provides healthcare professionals with knowledge to understand the Australian NPs role & scope of practice.	Australian NPs: 1. Effectiveness of NPs roles. 2. Roles will be expanded into future research & education of undergraduates.
<b>Campbell &amp; Duddle 2010</b>	Health literacy (HL) in education for patients with CKD.	Literature Review	Australia	Patient health literacy: 1. A determinant of chronic disease management. 2. Can effect preservation of renal function in stages of CKD. 3. Healthcare identified	Strength: This is a timely review as HL is a relatively new concept. Nurses can explore HL & put into practice e.g. patient & carer dissemination of	Provides an overview of the important link between HL & people living with CKD to current nephrology nursing practice.



				health literacy as a strategy that improves quality of healthcare in Australia.	information into knowledge. Empowering patients to self-management & informed decision making.	Identifies how HL has influenced other populations with chronic disease, in self-management issues.
<b>Chamney et al. 2012</b>	Reporting outcomes from a centre of excellence. University based quality initiative (QI) of patient, carer & educator collaboration.	Report on this primary QI. Qualitative evaluation of patients & carers stories of their involvement. Includes literature supporting QI.	UK	Qualitative evaluation of patients & carers stories Themes: 1. Involvement in research. 2. Patient' & carers' experience. 3. Providing a "voice" to patients & carers. 4. The value of learning from patient & carers experiences. 5. A good model for patient & carer involvement. 6. Personal benefits.	Limitations: 1. Small qualitative evaluation of patient & carer involvement & experience. 2. Academics & clinicians involvement & experiences were not represented. Strength: A first internationally in providing direction, to improve research & education in the area of "kidney care".	Research results reveal patient & carer involvement in education & research challenges well established perceptions & attitudes of healthcare professionals. Patient & carers involvement in education & training of students. Promoting a patient-centred approach.
<b>Cho et al. 2012</b>	Evaluation of multidisciplinary pre-dialysis education (MPE) in patients with CKD.	Retrospective single centre study. 1. Propensity score matching. 2. Comparison	Korea Participants: N=298 Patients with CKD pre-dialysis. 149 received	No differences found in comparison relating to patient mortality of the two groups. Patients who received MBE experienced reduced urgent start of RRT, shortened hospital	Weaknesses: As an observational study, it limits possible specific elements that may have affected beneficial outcomes of MBE.	MBE through a multidisciplinary approach promises to empower patients living with CKD to self-manage more

		of incidences of RRT, mortality, cardio-vascular events & infection.	MPD 149 did not receive MPD.	stays, better metabolic status on commencement of RRTs, lower incidence of cardiovascular events & infection.	Limitations: Single centre study. Although patients were followed up after initiation of RRT i.e. 30 months later this is a relatively short time to assess potential advantages of MBE.	effectively hence, reducing complications & enhancing QOL & wellbeing.
<b>Chow et al. 2011</b>	Determine whether buttonhole cannulation technique in new establishes HD fistulas reduced complications & prolonged access life compared to usual practice i.e. rope ladder site rotation technique of cannulation.	Multicenter Prospective, open label randomised controlled trial (RCT).	Australia Participants: N=70 Urban group of HDU & SHDU.	Results: 1. Infection of cannulation sites occurred in four patients in the buttonhole group & one patient acquired an infection in the cannulation site in the laddering group. 2. Patients using buttonhole cannulation resulted in more formation of hematoma & infection. 3. Higher incident of comorbidity in the buttonhole group combined with nursing staff in the learning stages of buttonhole cannulation technique. This may have contributed to the study results.	Limitations; Small sample size Although multi-center study of SHDU & HDUs, they were from the same area of health & therefore utilised same protocols.	Studies have been numerous on this topic, varying greatly in the reports of their results. Australian perspective: Utility of buttonhole cannulation technique, in Australia has gradually lost the favour of nephrology healthcare professionals & patients. This may be largely due to increased infection rates & morbidity rate of patients who have

						used this technique.
<b>Clarkson &amp; Robinson 2010</b>	Explore the lived experience of patients with ESKD to determine if they are adequately educated about their illness so far as to avoid the possible complications associated with this disease. Question: To what degree patients with ESKD were informed of lifestyle changes, possible complications, diet restrictions & protocols for dialysis?	Patient Interviews: 5 open ended questions. Analysis: Thematic analysis, Interpretive.	USA Participants: N=10 Patients 18 years & over- 6 receiving HD therapy. 4 receiving peritoneal dialysis.	Findings: - ESKD triggers - Life-style changes. Restricted life: limited travel options, strict schedules, restriction of diet & fluids, limits income, high costs in medical. 2. Limitations: Forces one to put plans on hold, limits social contact, reduces activities & makes one dependent on others. 3. Mind, body & spirit: Patients suffer from depression, lack strength or energy & fatigue. Patients cope relying on support system: Family, friends, support groups, church, prayer & God. Areas Lacking (gaps). 1. Healthcare management: Life changes affect both the patient & their carers. 2. Education: Medication regimens & side effects of dialysis	Strengths; The author proposes although a small sample size, there were various ages, years of & experience receiving RRT. Limitations: A larger sample may have added more diversity e.g. patients with renal transplant.	Lack of knowledge was perceived by patients as a large cause of where the patients had found themselves at their present state of health, living with ESKD. Knowledge was perceived as an empowering tool needed to stabilize their present health. Hence, timely education can empower patients & carers to consider treatment options, make informed decisions & achieve better outcomes. Through patient becoming empowered they can achieve

				therapy. 3. Preparing next generation: Emphasis on early treatment & early detection of CKD & training.		enhanced self-caring and management.
<b>Curtin et al. 1997</b>	Patients living with ESKD, achieving levels of compliance to therapeutic regimens & rehabilitation.	Literature review	USA	Compliance is multifaceted: There is a relationship between a patient's perception of personal independence and or sense of control. Compliance to prescribed medical regimens & rehabilitation status: 1. Chronicity of the disease. 2. Volume of medications patients are required to take. 3. Patients can be unsure of reasons & rationales for many of their treatments as they may not be apparent or comprehensive. 4. The fact the need for such treatments is lifelong & burdening.	Limitations: Carer's role not investigated.	Supporting patients empowered to self-care & manage can also improve their sense of control and hence level of adherence to treatment regimens.

<b>Dinwiddie et al. 2013</b>	To aid nephrologists & primary care health professionals to prevent adverse HD vascular access outcomes.	Literature review	USA	<ol style="list-style-type: none"> <li>1. Nephrologists are the patient's team leader &amp; therefore are responsible for patients VA management / outcomes.</li> <li>2. Success of any VA depends of its functionality for repetitive cannulation &amp; adequate blood flow rate (BFR) delivery of the dialysis pump.</li> <li>3. Cannulation is both an art &amp; a science.</li> <li>4. Innovations in cannulation of patients VA must be evidenced-based.</li> <li>5. Optimizing best-practice in cannulation leads to increasing VA &amp; patient survival as an outcome of decreasing cannulation-related adverse events.</li> </ol>	<p>Limitations:</p> <p>The authors identified most of the advice was anecdotal. Validating practice advice by anecdotal evidence, i.e. low level of evidence was what most current nursing literature utilised.</p>	<p>Patients rely on their nephrology team for their QOL &amp; wellbeing. Patients who are empowered to self-care &amp; likewise self-cannulate, can enhance the functionality of their VA, hence healthcare outcomes, QOL &amp; wellbeing</p>
<b>Feddersen &amp; Roger 2012</b>	Surveillance of the patient's arteriovenous fistulas (AVFS) requires a multidisciplinary approach & therefore is the responsibility of all persons	Literature review	Australia	<ol style="list-style-type: none"> <li>1, Cornerstone of surveillance is regular monitoring by physical examination of the patient's AVF/limb &amp; therefore more resources need to be invested in developing skills of both nephrology trainees &amp; nursing staff.</li> <li>3. The role of a dedicated</li> </ol>	<p>Strengths:</p> <p>The authors point out that the responsibility of a patient's VA surveillance is a shared responsibility of those involved in the patient's care. Hence enhancing the functionality of a patient's AVF.</p>	<p>Future research:</p> <p>Stenosis diameter &amp; effect of blood flow through the AVF.</p> <p>Lack of current agreement of best practice for surveillance of patients AVFs, e.g. agreement on the</p>

	involved in the patient's care, i.e. their healthcare team.			<p>VA nurse coordinator can assist in a patient's transition when reaching ESKD &amp; commencing haemodialysis therapy. Roles would include also educating &amp; training of staff.</p> <p>2. VA blood flow: direct surveillance e.g. using the gold standard ultrasound (US) dilution techniques. However this requires serial measurements (trends). Results are subject to variability of needle placements in the patients VA vessel. Direct measurement of VA blood flow e.g. MRI or Doppler US has additional advantage as these more expensive modes also provide anatomical information.</p>		<p>definition for "cut-off" measurements to define stenosis for diagnostic investigations, to correct a stenosis &amp; prevent thrombosis of a patient's AVF leads to decreasing risks of patient morbidity &amp; mortality.</p>
<b>Fluck &amp; Kumwenda 2011</b>	Renal Association Clinical, practice guidelines (CPGs) for patients with CKD, VA care.	CPGs Literature review	UK	<p>1. VA is a key component of a patient's HD therapy.</p> <p>2. An ideal access should allow for the safe &amp; effective removal &amp; return of blood through the extracorporeal circuit.</p> <p>3. A patient's VA should be</p>	<p>Strengths:</p> <p>The authors substantiate CPGs with rational &amp; a Grade system (1-4) &amp; (A-D) as a level of expert recommendation with an aim of maximizing</p>	<p>CPGs which are proficient in providing substantial direction to nephrology health professionals, patients &amp; carers</p>

	Update 2007 CPGs by the Renal Association Clinical Practice Guideline Committee.			easy to utilise/cannulate. However these goal remain difficult to achieve e.g. due to barriers such as vascular diseases.	applicability to standard clinical practice dependent on strength of recommendation & level of evidence. Grading was provided according to balance of benefit, risk, burden & cost.	can enhance patient health outcomes, QOL & wellbeing.
<b>Godbold 2013</b>	Explore the patient & carers perceptions of knowledge & safe care of the patient's AVFs. To explore compliance to healthcare practitioner's instructions.	Participants: Patients & carers. Conversation in established "online forum" groups. Analysis: Discourse analysis.	Australian Research. Participants: Internationally from six renal discussion groups: Patients & carers living with ESKD N=120	Patients & carers living with ESKD in conceptualizing their knowledge & role in their own care had sometimes seemed to have had better understanding of their personal situation. Therefore had more at stake in their outcomes of healthcare. Hence setting tasks of supervising & double checking the work of their healthcare professionals. Attempting to stop healthcare professional undertaking practices which are not compliant with best practice. An inversion of the expected loci of expertise in the patient-practitioner relationship. It may be difficult to label	Strengths: Patient established online forums were chosen as they may have been less self-censored than institutional set up patient & carer forums. The researcher emerging herself in the discussions. The researcher disclosed to the participants on each forum that she was a researcher & spouse of a patient whose RRT was a renal transplant. The researcher had spent weeks prior commencing the project reading forum discussions before joining discussions &	1. Compliance what this concept meant to patients over lengthy periods of time, as a concept it is non- static. 2. The concept of empowerment for patients & carers can improve patient outcomes & increase their sense of control over their situation. Drawback: Includes that a patient can only control their situation to a certain extent depending on the physical

			<p>patients &amp; carers as consumers as they may not be in a situation to easily “shop around” &amp; choose treatment centers &amp; practitioners e.g. due to urgent start on RRTs, inflexibility of healthcare systems.</p> <p>Not all patients want to be in control of their care. Patients &amp; carers who had engaged in these forums, the author reported were bio-medically informed, particularized having experiential knowledge, goals of safety &amp; longevity. And had encouraged others to watch treatments &amp; double check the work of their practitioners.</p> <p>Due to the chronicity of their disease, patients had time &amp; motivation to learn to interpret medical knowledge.</p> <p>Seeing themselves as being in a positions of authority had told of their experiences of having to protect themselves from the healthcare</p>	<p>reported no obvious change in discussion from her participation.</p> <p>Weaknesses:</p> <p>Possible personal bias of the researcher as a self-professed patient spouse although as they suggested this may also provide strength in the researchers findings.</p> <p>Information regarding the patient’s &amp; or carer’s demographics may have added a richer understanding of the concept explored e.g. age, gender, mode of treatment &amp; VA, months/ years of receiving RRT, carers relationship weather receiving treatment in HDUs, SHDU or home dialysis.</p>	<p>limitations of their illness, power of practitioners to diagnose, choice of the patient treatments &amp; ability to perform procedures.</p> <p>Not all practitioners welcome patients &amp; carers who “know too much” during decision making processes.</p> <p>Requires patients &amp; carers to be empowered.</p> <p>However, this can result in causing antagonism &amp; frustration for patient’s and carers.</p> <p>Balancing one’s safety, not losing faith in healthcare professionals can conflict with one’s goals.</p> <p>Tensions in compliance raises the question of how quality of</p>
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				professionals around them. Compliance was about juggling interrelation issues, adherence to medical regimens, self-maintenance of one's health & identifying compliant healthcare staff.		care is maintained for patients less able & or desiring to be involved in decision making processes about their healthcare needs & options.
<b>Hagren et al. 2005</b>	Examine how patients receiving HD therapy for ESKD express their life situation focusing on how treatment encroaches on time and place, how patients experience care.	Interviews. Analysis: Qualitative content analysis was transcribed & collated into 3 themes & 4 sub-themes.	Sweden Participants N=41 Patients With greater than 3 months experience in receiving their HD therapy. 15 women 26 males	Three main themes: 1. Not finding space. Patients reported feelings of not having the ability to live life to the full feeling that their illness encroaches making demands & both their time & physical ability. While prohibited them from taking part in normal activities. Subthemes: Struggling with time-consuming care: Patients reported HD therapy was necessary for their survival, however had consumed so much of their time. Sub-theme: Feeling that life is restricted. Patients expressed how tiring the illness was &	Limitations: Single centre. Possible weakness: Researcher's own perceptions. Strength: Strong insight into patients lived experiences & perceptions.	Patients can be further restricted hence disadvantaged by their illness & treatment regimens, by the additional changes to their life styles, perceptions & behaviours of their healthcare givers & feelings of vulnerability.

				<p>how it restricted them from being able to fully participate in society. Their illness &amp; its treatment imposed on their sexual, marital, psychological, financial, work &amp; holiday restriction on these patients.</p> <p>2. Feelings evoked in the care situation Sub-theme: Sense of emotional distance.</p> <p>Contact with the patient's healthcare practitioners is problematic as professionals have restricted time with patients and therefore lack time to educate patients. Or patients have feelings that care givers keep emotional distances, having little understanding or empathy for the patient's situation.</p> <p>3. Attempting to maintain manageability of restricted life.</p> <p>Sub-theme: Feeling vulnerable.</p> <p>Vulnerability was twofold, from the consequences of the illness &amp; a result of the</p>		
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				patient to be dependent on care givers.		
<b>Kastrouni et al. 2010</b>	Evaluate QOL of patients living with ESKD receiving RRT in Greece. To understand whether & how their QOL can be improved. Understanding what the diagnosis of chronic disease such as ESKD, results in changes to patient's lives.	Interviews, The SF-36 Short Form, questionnaire, Search of patient medical records. Analysis: Statistical analysis: Student's t-test for unpaired data & chi-square test as appropriate.	Greece Participants N=93 Patients receiving HD therapy in two separate HDUs. 38 females 55 males Age 18 -85 years	Comparisons between this study & a similar study reported in the USA, using the SF-36 Short Form Questionnaire pertinent to nephology patient care, had revealed that in both studies the lowest scores were as a result of the effects of ESKD reported as employment & sexual function. However, these two topics in the USA study had been significantly less important. However, 100% of USA participating patients had answered the relevant question, with only a comparison of 51% of Greek patients. In questions relating to patient's emotional status USA patients had significantly higher scores. Lowest scores for the Greek population were for questions related to physical function & physical achievements in	Weaknesses: Two HDU centres Some patient interviews were in the hospital environment & some patient interviews were carried out in the patient's home. Where the authors had reported that they were accompanied by family members. This may have resulted in some bias when family members voicing their perceptions related to each other. However, the authors reported interviews were carefully controlled.	Populations from different countries may perceive QOL at many similar levels however, cultural differences & environmental differences of care giving / receiving may result in differences in the perceptions of patients living with ESKD.

				<p>daily life, general health &amp; emotional status.</p> <p>Greek population scored much higher results in questions relating to energy/ fatigue, physical functioning &amp; emotional status.</p> <p>Questions that related to pain were similar in both populations.</p>		
<b>Key 2008</b>	<p>Phenomenon of interest: 'What is the nature of current evidence related to the effect of early pre-ESKD education &amp; the availability of RRT modalities on the choice of self-care RRT modalities?'</p> <p>Goal: To increase awareness about pre-ESKD education</p>	Literature review	USA	<p>CMS recommends early referral of patients with CKD for education of all modalities of RRT. Importance of knowledge for patient is for their empowerment &amp; to have choices availability of RRT options.</p> <p>Late referral frequently results in patients missing the opportunity of pre-ESKD education. Secondly, these patients are at high risk of commencing HD therapy with a suboptimal dialysis central venous catheter (DCVD).</p> <p>Therefore, worldwide, healthcare professionals need to ensure that there are pathways to promote</p>	<p>Strengths:</p> <p>The author comes from the lived experience as the spouse of a patient with ESKD receiving dialysis.</p> <p>This review examines a multifaceted phenomenon, assesses the barriers &amp; puts forward doable solutions &amp; plans, to increase patient empowerment from</p>	<p>Early referral closes a "gap" increasing the likelihood of timely education. Enabling the patient to be empowered to make informed choices, hence gain control of their care.</p>

	programs, examine barriers to early pre-ESKD education & introduce programs designed to decrease late referral from nurses & other healthcare providers.			early referral to nephology & early pre-ESKD education.		
<b>Kring 2008</b>	Describe QOL of persons with ESKD & examine factors that affect their QOL.	Cross-sectional, correlated non-experimental study of a convenience sample of patients living with ESKD. Patient medical records.	USA Participants: N=73 55% female 45% male 76% African American 67% not married 56% had incomes above federal poverty level 56 years mean age 56 months mean time receiving HD therapy.	QOL may be better predicted from psychological factors rather than physiological factors. Only health-related variables of anxiety, depression, general health perception, & albumen significantly ( $p<.05$ ) contributed to patients QOL. The author reported that when all variables were included in the model, 61% of the variability in overall QOL was explained.	Limitations: A small sample Strengths: Good exploration of this group of patient's personal perceptions of QOL of a population of patients living with ESKD. Results of the study will assist investigators to begin studies that research trajectory of monitoring QOL & influencing factors. Quantification of QOL may assist researchers in determining the trajectory of the terminal phase of patient's chronic illness.	Future studies: The author also proposes further studies should continue to identify factors that influence patients with ESKD & determine interventions that enhance a person's sense of wellbeing. As well as illuminate the relationship between QOL & end of life.

<b>Lopez-Vargas et al. 2011</b>	Explore barriers to timely AVF creation. Identification of barriers and enablers to timely patient AVF placement.	Multi-centre cohort study. Mixed methods of qualitative and quantitative analysis. Prospective data collection, including data concerning pre-dialysis education, interviews of centre staff, referral times, a patient's estimated glomerular filtration rate (eGFR) at AVF & start of HD therapy.	Australia and New Zealand. Participants 9 nephrology centres across Australia and New Zealand.	During a 6 month period 319 patients commenced HD therapy 39% with an AVF and 59% using a DCVC. Barriers to timely AVF creation and starting HD therapy with an AVF as the patient's VA were perceived as: 1. Lack of formal policies for referral. 2. Long waits for surgical review and AVF creation 3. Lack of a data base for the purpose of to managing patients. The best results were from centres that had organized programs for patient pre-dialysis care pathways from CKD to ESKD. Centralized patient data bases and low patient-nephrologist ratios.	Limitations: A limited number of patient-barriers were assessed. Only cross-sectional data was correlated.	Future research could look at patient and carer factors as barriers to early and timely education, decision-making processes and AVF creation.
<b>Mitrou et al. 2013</b>	Explore and discuss the effects of exercise training on depression of	Literature Review	Greece	QOL for patients living with ESKD, is poorer than the general population due to mental, social & physical problems which are often associated with patient's	Limitations: No exploration or discussion of exercise programs being initiated as part of pre dialysis educational	Future Research: Define composition of exercise programs including duration,

	patients living with ESKD.			ESKD and or RRT of HD therapy or peritoneal dialysis. Patients suffering with depression have poorer QOL and are at higher risks of mortality. Exercise training, is an effective & safe treatment for both depression & other health related factors for patients living with ESKD. Systematic, long-term, intra-dialytic exercise programs may have the most benefit for this group of patients.	programs.	frequency, intensity & percentage of total patient workload to assess value of exercise programs for the patient.
<b>Moist et al. 2008</b>	1. To evaluate the effect of 1-way travel time to HD therapy on mortality, health related (HR) QOL, adherence, withdrawal from dialysis therapy and transplantation . 2. Examine the association between travel time and pre-dialysis care &	Prospective observational cohort-study. Questionnaire.	Participants N=20,994 Patients living with ESKD receiving HD therapy. 1996-2001: 10,775 responses Randomly selected from 307 representative dialysis facilities in 7 countries France, Germany, Italy,	Longer travel times were associated significantly with greater mortality risk and decreased HR-QOL. Exploring opportunities to decrease travel time should be incorporated into the dialysis clinical routine.	Limitations: More countries involved in second study carried risk of duplication and thereby distorting results, unless strict criteria was in place to check for patient duplication as respondents. Non response rate was substantial. 25.9% of 28, 323 patient replies did not complete. Therefore 7,347 were dis-guarded. Non responders were older patients with	Longer travel time resulting in patient non-adherence and reduction of haemodialysis hours increases patient risk of mortality. This can be improved therefore modifiable risks.

	performance targets on dialysis therapy.		Japan, Spain, USA and UK. 2002-2004: 10,2019 responses Randomly selected. Same countries as previous study with an additional 5 countries Australia, New Zealand, Belgium, Canada and Sweden.		more co-morbid conditions Time travel was assessed by using a single non-validated question.	
<b>Moist et al. 2012</b>	Optimising VA for haemodialysis in the elderly patient.	Literature review	Australia, Canada and USA	Elderly patient with CKD have a unique set of considerations and challengers when planning their VA for haemodialysis which may include rate of decline of renal function, co-morbid conditions and vascular biology timing & initiation of haemodialysis, social issues & life expectancy. Decision making and care are important factors in determining the most appropriate VA for the	Strengths: Comprehensive review.	This information can provide relevant guidance to individualise & optimize care that may reduce patient risks of morbidity, mortality. Improving QOL in the elderly patient population living with CKD-ESKD & haemodialysis therapy.



				individual elderly patient.		
<b>Naik et al. 2012</b>	Outcomes based on numeric performance measures that are of great value to the clinician, may not be shared/valued by the patient.	Literature review	USA	<p>HR-QOL is important to the patient living with ESKD, however there are time constraints for their healthcare providers. Structured HR-QOL may allow patient's dialysis focused healthcare team to identify and target care for these patients who frequently have a higher symptom burden.</p> <p>HR-QOL can use patient data in many domains of care, data can be used to improve the individual patient's perceived and actual care. As perceptions of care are very important to a patient &amp; their care providers. Patient adherence to prescribed medical treatments correlates closely when patients are satisfied with their care.</p>	Strengths: Proposes more patient oriented values of determining patient HRQOL.	Until electronic medical record technologies are optimal for collation of patient data &, both feasibly priced & implemented, patient data should not be collected using lengthy questionnaires. Utilizing a philosophy of asking patients about their most pressing concerns. Closely monitoring the patient-reported outcomes and corresponding to the patient's concerns, promises to provide an approach that provides a more

						patient-centred care for patients living with ESKD.
<b>Polkinghorne et al. 2009</b>	Examines the effect of a nurse VA coordinator in reducing DCVC incidence in patients receiving HD therapy	Quality improvement (QI) report, prospective before and after study. Measurement of study data: Number of patients who commenced HD therapy with an AVF being use as their VA.	Australia N=184 Patients commencing HD therapy 2005 & 2006.	Pre study data had shown poor overall coordination of surgical waiting lists of patients for VA. The QI resulted in significantly increasing the incidence of patients commencing HD therapy using an AVF instead of a DCVC by improving the overall coordination. QI plan included a nurse VA coordinator and an algorithm to prioritize patients waiting for surgery. Overall 65% of patients commenced HD therapy using an AVF as their VA, compared to 2% of patients using an arteriovenous graft (AVG) & 33% with a DCVC.	Limitations: A non randomised study.	Healthcare systems may differ in feasibility of implementing such QI. It would require cooperation of multidisciplinary team including surgeons to prioritise patients depending on assignment QI report. QI had shown significant outcomes for patient VA management.
<b>Polkinghorne 2013</b>	Kidney Health Australia- Caring for Australians with Renal Impairment	Clinical Practice Guidelines (CPGS) Literature review.	Australia	Scope of CPGs: Addresses topics of insertion of DCVCs, surgical creation of AVFs & surgical insertion of AVGs. Prevention of infection,	Limitations: Level of evidence.	Patient should be referred to a nephrologist and vascular surgeon early as time is required to allow

	(KHA-CARI) Guidelines for patient VA for HD therapy AVF, AVG and DCVC. Guideline objective: Review and summarize the evidence on selection of type of VA including reference to mortality, access type, access patency and cost.			treatment and nursing care.		for patient education, surgical assessment, VA creation and subsequent maturation of the patients AVF or AVG.
<b>Porter et al. 2013</b>	Education of patients with progressive CKD requiring an acute start to dialysis therapies.	Literature Review	Canada	Education of patients is a critical component of care which involves managing and treating patients. Tailoring patient education to the individual and their readiness to learn. Healthcare professionals should understand the chronicity of CKD and the enormous effect CKD has on patient's lives. Strategies such as suggested by the authors	Strengths: As many patients have a suboptimal urgent start of RRT, this model for translation of knowledge, has utility in giving back control to this group of patients and carers for understand options and taking part in decision making processes about the patient care and management.	Empowering patients through individualized healthcare education. The challenge for nephrology healthcare providers is knowing when and how to begin the patient's education and tailoring

				can assist healthcare professionals to provide patients with such models of education and support to the individual patient when experiencing the need to have an urgent start to dialysis therapies and require ongoing RRTs. Enhancing their involvement and empowerment in the decision making processes.		education to the stage of patient's readiness to learn. Focusing on patient's individual needs.
<b>Richard &amp; Engebretson 2010</b>	Describe the patient's experience of receiving HD therapy via an AVF. Describe the patient's day to day experience of living with an AVF. Identify specific patient concerns related to caring for and maintaining their AVF.	Qualitative ethnographic study: Semi-structured interviews lasting 1.5-4hrs, field notes & artefacts. Data Analysis: Interpretive. Thematic.	USA N=14 Patients receiving HD therapy.	Overarching theme: Vulnerability, with an underlying theme of body awareness. Vulnerability was based of patients having ESKD, requiring dialysis and being dependent on their VA functionality along with the healthcare system for their survival. The result of being vulnerable was the patient's need to be both continually vigilant and assertive in order to protect one self. This dependency frequently leads to situations where patients mistrusted the healthcare system both as	Limitations: Small sample size.	Patient's perceptions and experiences living with and their VA in the context of HD therapy, caring for and maintaining the viability of their VA with HD therapy are complex processes. While the stigma patients reported in relation to their VA, was an important issue that had evoked their greatest

				far as their HD therapy & the care of their VA was concerned. Patients mistrust focused on technology as well as their healthcare providers e.g. the nurses, technicians and physicians. Patients also reported their concerns about experiencing pain when their VA was cannulated. Patients reported their concerns about disfigurements to their body, a result of having VAs, triggering internal & external stigma about their VA.		emotional response.
<b>Theofilou 2011</b>	Patients who experience depression. Effect of depression on patient's health and their adherence to their prescribed CKD medical regimen.	Case Report	Greece	Patient depression was associated with "learned helplessness" a condition where the patient believes no behaviour will achieve their desired outcomes. Patients living with CKD face many challenges, increasing their probability that they will develop depression or anxiety or worsen these conditions. Including a general feeling of unwellness. The patient may experience specific	Strengths: Strong research method for exploration of depression in patients with CKD. Limitations: comparison incidence of depression of patients receiving alternative modalities of RRT may have provided further insights.	Common symptoms of depression: Dysphoric mood, somatic concerns, difficulty concentration, loss of interest or pleasure, decreased or increased appetite, weight change, sleep disturbances, psychomotor

				<p>symptoms as a result of their CKD or treatments, disruptions to their lifestyle, need to adhere to medical prescriptions, fluid restrictions, hospitalizations and a shortened life-span. Consequently, depression is the most common psychiatric disorder reported among adult patient living with CKD. Depression is linked with reduced self-efficacy.</p>		<p>agitation or retardation, fatigue, aches &amp; pains, guilt, feelings of worthlessness, suicidal ideation, or preoccupation with death.</p>
<p><b>Tims et al. 2007</b></p>	<p>Establish current understanding of empowerment and how it may relate to care of people living with ESKD.</p>	<p>Literature review. Themes and Concept analysis</p>	<p>Australia</p>	<p>Themes:</p> <ol style="list-style-type: none"> <li>1. The elements of the concept of empowerment.</li> <li>2. Empowerment in nursing and nursing education.</li> <li>3. Empowerment of patients with ESKD.</li> </ol> <p>Elements of the concept of empowerment:</p> <ol style="list-style-type: none"> <li>1. Self- determination.</li> <li>2. Partnership (power sharing).</li> <li>3. Effective communication.</li> <li>4. Goal setting.</li> <li>5. A caring environment.</li> <li>6. Social-political</li> </ol>	<p>Strengths:</p> <p>Holistic perspective of empowerment.</p>	<p>Future research:</p> <p>Incorporating the seven elements of empowerment into their studies of empowerment in relationship to caring for patients living with ESKD.</p>

				awareness. 7. Construction of knowledge.		
<b>Tordoir et al. 2007</b>	Evidence based practice guidelines (EBPG)	EBPG for patients with CKD, VA care	UK and Europe	<p>Example:</p> <p>Patient referral:</p> <p>Guideline 1.1 An early plan for venous preservation should be a substantial part of pre-dialysis care and education in CKD for patients, regardless of the choice of treatment modality (Evidence level IV)</p> <p>Guideline 1.2 Every patient with CRF who has opted for HD therapy, should start dialysis with a functioning vascular assess (Evidence level III)</p> <p>Guideline 1.3 Potential patients for chronic HD therapy, should ideally be referred to a nephrologist and / or surgeon for preparing their VA when they reach the stage 4 of their CKD eGFR is &gt;30 mls/minute/1,73 m<sup>2</sup> or earlier in cases of rapid progressive nephropathy or specific clinical</p>	<p>Strengths:</p> <p>In view of lack of high levels evidence these EBPG provide substantial guidance for nephrology healthcare.</p>	<p>Future Research:</p> <p>into the development of new non-thrombotic grafts and the prevention of IH remains necessary</p>

				conditions such as diabetes or severe peripheral vascular disease.		
<b>Wilson et al. 2010</b>	Explore the concept of the haemodialysis nurse remaining the “perpetual novice” and factors impeding advancement of AVF skill acquisition.	Qualitative study. Methodology: Ethnographic 45-60 minute interviews 8 item semi structured interview	UK Participants: N=9 Nurses with 6-23 years nursing experience prior working in the HDU, 6-9month period working in the HDU and working part time or casual. Single centre HDU Purposeful. Nurses volunteered as novice cannulators.	Themes: 1. Personal factors: Approach to learning. Emotional reaction to cannulation. Interpersonal relationships between HD nurses. 2. Environmental / contextual factors: Limited learning opportunities. Patients invested in their AVF. Continuity / plan of care issues.	Strengths: Interesting exploration into the cultural environment of the HDU. Limitations: Single centre HDU. Only 9 out of potential 85 nurses participated in the study.	Future research: Implications of perpetual novice phenomenon and possible broader applicability beyond nephrology nursing practice. Outcomes of interventions of this phenomenon. Improving nursing work environments building interpersonal relationships among nurses, results in positive outcomes for their patients i.e. those receiving HD therapy.
<b>Zalai et al. 2012</b>	The burden of CKD resulting in depression and the increased risks	Literature review	Canada & Hungary	Depressive disorders are 1.5-4 times more prevalent in medically ill patients than in the general population.	Strengths: Comprehensive review of literature on the concept of depression in patients living with	Depression is a high risk factor for this vulnerable population. The burden of



	for patient health and QOL.			<p>Symptoms of depression affect approximately 25% of patients receiving HD therapy for ESKD and can be associated with poor QOL &amp; mortality. Depression increases and is more likely to create risk factors of poorer outcomes for this group of patients. Such as VA failure and patient death after receiving a renal transplant. The high impact of psychological distress in patients during the final / advanced stages of CKD. Impacts on patients CKD outcomes therefore demands for patient screening and intervention is integrated into patient's routine care.</p>	CKD and their QOL, having a fallout effect on their families QOL.	<p>CKD imposes psychological distress on the patient right from the early stages of the disease. Some patients learn to cope over time, while one in four individuals can struggle at any stage of CKD with depression. Both the patient and their family can suffer with poor QOL when the patient experience severe symptoms of subclinical depression.</p>
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## **Appendix 6...Site specific participant information sheets**

### ***Site specific participant Information sheet for patients***

#### **Case Study: Vascular access management for patients requiring haemodialysis in a satellite haemodialysis unit clinical setting.**

##### **Invitation**

You are invited to participate in a research study into the management and care of patient vascular access for haemodialysis. To do this we are undertaking a questionnaire.

The study is being conducted by three researchers at the University of Tasmania:

Mrs Debi Cowan

Dr Lindsay Smith

Associate Professor Josephine Chow

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully.

##### **1. 'What is the purpose of this study?'**

The aim of this study is to understand the patient's experience during management of their vascular access for haemodialysis in a satellite haemodialysis unit. We hope this will help us to find ways that may enhance vascular access care through the development of vascular access management guidelines.

##### **2. 'Why have I been invited to participate in this study?'**

You have been invited to participate in this study because of your experience of having a vascular access of an AV fistula or graft for haemodialysis. This study is an opportunity for you to have your say and help determine clinical practices for patient's vascular access management and care.

Site Specific Participant Information Sheet for Patients

**3. 'What if I don't want to take part in this study or if I want the information provided withdrawn later?'**

Participation in this study is voluntary. It is completely up to you whether or not you participate. Whatever your decision, it will not affect your relationship with staff as a patient. The questionnaire is voluntary and your non participation will not impact upon the relationships, healthcare care or the treatment you receive now or in the future related to your vascular access. You are free to withdraw from the study if you wish by not completing the questionnaire. However, once you have completed the questionnaire it will not be possible to withdraw your data.

**4. 'What does this study involve?'**

If you agree to participate in this study, you will be asked to complete a questionnaire. We expect that completing the questionnaire will take 30 minutes of your time as it consists of a mix of tick box and short answer questions.

**5. 'How is this study being paid for?'**

The study is being sponsored by the University of Tasmania and no money is paid directly to individual researchers.

**6. 'Are there risks to me in taking part in this study?'**

As this study involves providing information through the voluntary completion of a questionnaire there are no perceivable risks through participation in this study presently or in the foreseeable future.

**7. 'Will I benefit from the study?'**

This study aims to increase knowledge which may enhance future management and care of patients vascular access.

**8. 'Will taking part in this study cost me anything, and will I be paid?'**

Participation in this study will not cost you anything and there is no payment.

**9. 'How will my confidentiality be protected?'**

The questionnaire is anonymous and returned to the researchers through a sealed envelope. You are not asked to provide any identifying information.

Site Specific Participant Information Sheet for Patients

**10. 'What happens with the results?'**

The anonymous data will be kept for five years after the first publication results and then the electronically stored data will be destroyed.

**11. 'What should I do if I want to discuss this study further before I decide?'**

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**12. 'Who should I contact if I have concerns about the conduct of this study?'**

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- South Western Sydney Local Health District, any person with concerns or complaints about the conduct of this study may also contact the Research Governance Officer on (02) 8738 8304, email: [research.support@sswahs.nsw.gov.au](mailto:research.support@sswahs.nsw.gov.au) and quote project number [xx/xxx]

and/ or

- Tasmanian Health and Medical Human Research Ethics Committee. Contact the Executive Officer of the HREC (Tasmania) Network on (03) 6226 7479 or email [human.ethics@utas.edu.au](mailto:human.ethics@utas.edu.au). The Executive Officer is the person nominated to receive complaints from research participants. You will need to quote H0013590.

**Thank you for taking the time to consider this study.**

**If you wish to take part in it, please return the questionnaire in a sealed envelope to the person who gave this information sheet to you. This information sheet is for you to keep. Your consent will be implied by completion and submission of the questionnaire.**

Site Specific Participant Information Sheet for Patients

## ***Site specific participant information sheet for family members or carers***

### **Case Study: Vascular access management for patients requiring haemodialysis in a satellite haemodialysis unit clinical setting.**

#### **Invitation**

You are invited to participate in a research study into the management and care of the patient's vascular access for haemodialysis. To do this we are undertaking a questionnaire.

The study is being conducted by three researchers at the University of Tasmania:

Mrs Debi Cowan

Dr Lindsay Smith

Associate Professor Josephine Chow

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully.

#### **1. 'What is the purpose of this study?'**

The aim of this study is to understand the patient's experience during management of their vascular access for haemodialysis in a satellite haemodialysis unit. We hope this will help us to find ways that may enhance vascular access care through the development of vascular access management guidelines.

#### **2. 'Why have I been invited to participate in this study?'**

You have been invited to participate in this study because of your experience knowing someone closely who has a vascular access and being involved in the healthcare of the person with a vascular access of an AV fistula or graft for haemodialysis. This study is an opportunity for you to have your say and help determine clinical practices for the patient's vascular access management and care.

#### **3. 'What if I don't want to take part in this study or if I want the information provided withdrawn later?'**

Site Specific Participant Information Sheet for Family Members or Carers

Participation in this study is voluntary. It is completely up to you whether or not you participate. Whatever your decision, it will not affect your relationship with staff as a family member or carer. The questionnaire is voluntary and your non participation will not impact upon the relationships, healthcare care or the treatment the patient receives now or in the future related to their vascular access. You are free to withdraw from the study if you wish by not completing the questionnaire. However, once you have completed the questionnaire it will not be possible to withdraw your data.

**4. 'What does this study involve?'**

If you agree to participate in this study, you will be asked to complete a questionnaire. We expect that completing the questionnaire will take 30 minutes of your time as it consists of a mix of tick box and short answer questions.

**5. 'How is this study being paid for?'**

The study is being sponsored by the University of Tasmania and no money is paid directly to individual researchers.

**6. 'Are there risks to me in taking part in this study?'**

As this study involves providing information through the voluntary completion of a questionnaire there are no perceivable risks through participation in this study presently or in the foreseeable future.

**7. 'Will I benefit from the study?'**

This study aims to increase knowledge which may enhance future management and care of patient's vascular access.

**8. 'Will taking part in this study cost me anything, and will I be paid?'**

Participation in this study will not cost you anything and there is no payment.

**9. 'How will my confidentiality be protected?'**

The questionnaire is anonymous and returned to the researchers through a sealed envelope. You are not asked to provide any identifying information.

**10. 'What happens with the results?'**

Site Specific Participant Information Sheet for Family Members or Carers

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Site Specific Participant Information Sheet for Family Members or Carers

## ***Site specific participant information sheet for healthcare professionals***

### **Case Study: Vascular access management for patients requiring haemodialysis in a satellite haemodialysis unit clinical setting.**

#### **Invitation**

You are invited to participate in a research study into the management and care of the patient's vascular access for haemodialysis. To do this we are undertaking a questionnaire.

The study is being conducted by three researchers at the University of Tasmania:

Mrs Debi Cowan

Dr Lindsay Smith

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Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully.

#### **1. 'What is the purpose of this study?'**

The aim of this study is to understand the patient's experience during management of their vascular access for haemodialysis in a satellite haemodialysis unit. We hope this will help us to find ways that may enhance vascular access care through the development of vascular access management guidelines.

#### **2. 'Why have I been invited to participate in this study?'**

You have been invited to participate in this study because of your experience of being involved in the healthcare of patients with a vascular access of an AV fistula or graft for haemodialysis. This study is an opportunity for you to have your say and help determine clinical practices for the patient's vascular access management and care.

#### **3. 'What if I don't want to take part in this study or if I want the information provided withdrawn later?'**

Participation in this study is voluntary. It is completely up to you whether or not you participate. Whatever your decision, it will not affect your relationship with patients, patient's family members or carers or your peers as healthcare professional. The questionnaire is voluntary and your non participation will not impact upon relationships now or in the future related to patient vascular access. You are free to withdraw from the study if you wish by not completing the questionnaire. However,

Site Specific Participant Information Sheet for Healthcare Professionals



once you have completed the questionnaire it will not be possible to withdraw your data.

**4. 'What does this study involve?'**

If you agree to participate in this study, you will be asked to complete a questionnaire. We expect that completing the questionnaire will take 30 minutes of your time as it consists of a mix of tick box and short answer questions.

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**Thank you for taking the time to consider this study.**

**If you wish to take part in it, please return the questionnaire in a sealed envelope to the person who gave this information sheet to you. This information sheet is for you to keep. Your consent will be implied by completion and submission of the questionnaire.**

## Appendix 7...Site specific full survey for patients

# Your Health and Well-Being

This questionnaire asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. *Thank you for completing this survey!*

For each of the following questions, please mark an ☒ in the one box that best describes your answer.

### 1. In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	2	3	4	5

### 2. Compared to one year ago, how would you rate your health in general now?

Much better now than one year ago	Somewhat better now than one year ago	About the same as one year ago	Somewhat worse now than one year ago	Much worse now than one year ago
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	2	3	4	5

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**3 The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?**

	Yes, limited a lot ▼	Yes, limited a little ▼	No, not limited at all ▼
a <u>Vigorous activities</u> , such as running, lifting heavy objects, participating in strenuous sports .....	<input type="checkbox"/> 1 .....	<input type="checkbox"/> 2 .....	<input type="checkbox"/> 3
b <u>Moderate activities</u> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf .....	<input type="checkbox"/> 1 .....	<input type="checkbox"/> 2 .....	<input type="checkbox"/> 3
c Lifting or carrying groceries .....	<input type="checkbox"/> 1 .....	<input type="checkbox"/> 2 .....	<input type="checkbox"/> 3
d Climbing <u>several</u> flights of stairs .....	<input type="checkbox"/> 1 .....	<input type="checkbox"/> 2 .....	<input type="checkbox"/> 3
e Climbing <u>one</u> flight of stairs .....	<input type="checkbox"/> 1 .....	<input type="checkbox"/> 2 .....	<input type="checkbox"/> 3
f Bending, kneeling, or stooping .....	<input type="checkbox"/> 1 .....	<input type="checkbox"/> 2 .....	<input type="checkbox"/> 3
g Walking <u>more than a kilometre</u> .....	<input type="checkbox"/> 1 .....	<input type="checkbox"/> 2 .....	<input type="checkbox"/> 3
h Walking <u>several hundred metres</u> .....	<input type="checkbox"/> 1 .....	<input type="checkbox"/> 2 .....	<input type="checkbox"/> 3
i Walking <u>one hundred metres</u> .....	<input type="checkbox"/> 1 .....	<input type="checkbox"/> 2 .....	<input type="checkbox"/> 3
j Bathing or dressing yourself .....	<input type="checkbox"/> 1 .....	<input type="checkbox"/> 2 .....	<input type="checkbox"/> 3

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**4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?**

All of the time	Most of the time	Some of the time	A little of the time	None of the time
▼	▼	▼	▼	▼

- a Cut down on the amount of time you spent on work or other activities ..... ☐ 1 ..... ☐ 2 ..... ☐ 3 ..... ☐ 4 ..... ☐ 5
- b Accomplished less than you would like ..... ☐ 1 ..... ☐ 2 ..... ☐ 3 ..... ☐ 4 ..... ☐ 5
- c Were limited in the kind of work or other activities ..... ☐ 1 ..... ☐ 2 ..... ☐ 3 ..... ☐ 4 ..... ☐ 5
- d Had difficulty performing the work or other activities (for example, it took extra effort) ..... ☐ 1 ..... ☐ 2 ..... ☐ 3 ..... ☐ 4 ..... ☐ 5

**5. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?**

All of the time	Most of the time	Some of the time	A little of the time	None of the time
▼	▼	▼	▼	▼

- a Cut down on the amount of time you spent on work or other activities ..... ☐ 1 ..... ☐ 2 ..... ☐ 3 ..... ☐ 4 ..... ☐ 5
- b Accomplished less than you would like ..... ☐ 1 ..... ☐ 2 ..... ☐ 3 ..... ☐ 4 ..... ☐ 5
- c Did work or other activities less carefully than usual ..... ☐ 1 ..... ☐ 2 ..... ☐ 3 ..... ☐ 4 ..... ☐ 5

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6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

Not at all	Slightly	Moderately	Quite a bit	Extremely
▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

7. How much bodily pain have you had during the past 4 weeks?

None	Very mild	Mild	Moderate	Severe	Very severe
▼	▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

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9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a Did you feel full of life? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
b Have you been very nervous?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
c Have you felt so down in the dumps that nothing could cheer you up?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
d Have you felt calm and peaceful?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
e Did you have a lot of energy?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
f Have you felt downhearted and depressed?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
g Did you feel worn out? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
h Have you been happy?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
i Did you feel tired? .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

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**11. How TRUE or FALSE is each of the following statements for you?**

	Definitely true ▼	Mostly true ▼	Don't know ▼	Mostly false ▼	Definitely false ▼
a I seem to get sick a little easier than other people .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
b I am as healthy as anybody I know .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
c I expect my health to get worse.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
d My health is excellent.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

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**12. How TRUE or FALSE is each of the following statements for you?**

Definitely true	Mostly true	Don't know	Mostly false	Definitely false
▼	▼	▼	▼	▼

- a When I first started haemodialysis treatment the different types and sites for vascular access (fistula or Vascath) were explained to me  
..... ☐ 1..... ☐ 2..... ☐ 3..... ☐ 4..... ☐ 5
- b When I first started haemodialysis treatment I was able to choose my vascular access type (fistula or Vascath) and site  
..... ☐ 1..... ☐ 2..... ☐ 3..... ☐ 4..... ☐ 5
- c When I first started haemodialysis treatment I was satisfied that I was able to contribute to the decisions that were made  
..... ☐ 1..... ☐ 2..... ☐ 3..... ☐ 4..... ☐ 5
- d I feel comfortable to stop treatment and discuss my concerns when I am not happy with a decision such as where to needle me  
..... ☐ 1..... ☐ 2..... ☐ 3..... ☐ 4..... ☐ 5
- e I am able to take part in discussions with the nurses about my haemodialysis treatment decision to have laddering or to have button hole sites  
..... ☐ 1..... ☐ 2..... ☐ 3..... ☐ 4..... ☐ 5
- f Now I am able to choose my vascular access type (fistula or Vascath) and site  
..... ☐ 1..... ☐ 2..... ☐ 3..... ☐ 4..... ☐ 5
- g I am able to take part in discussions with the nurses about my haemodialysis treatment decision of where to needle me  
..... ☐ 1..... ☐ 2..... ☐ 3..... ☐ 4..... ☐ 5
- h I have been given enough information about looking after my vascular access (fistula or Vascath) and site  
..... ☐ 1..... ☐ 2..... ☐ 3..... ☐ 4..... ☐ 5
- i I am asked during haemodialysis treatment if I would like my family / carers to be involved  
..... ☐ 1..... ☐ 2..... ☐ 3..... ☐ 4..... ☐ 5
- j My family / carers have a role to play in contributing to the management of my vascular access (fistula or Vascath) and site  
..... ☐ 1..... ☐ 2..... ☐ 3..... ☐ 4..... ☐ 5

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Each of the traits listed below deal with an important aspect that some people think contributes to the health and wellbeing of individuals. Please circle a number (1 through to 5) that best describes **how satisfied** you are with how members of your **health care team** demonstrate these traits towards you.

	Very Dissatisfied	Somewhat Dissatisfied	Generally Satisfied	Very Satisfied	Extremely Satisfied
Appreciation and affection	1	2	3	4	5
Commitment	1	2	3	4	5
Positive communication	1	2	3	4	5
Enjoy spending time together	1	2	3	4	5
Encourages spiritual wellbeing	1	2	3	4	5
Successfully manage stress and crisis.	1	2	3	4	5
Encourages physical wellbeing	1	2	3	4	5

How satisfied you are with these aspects of your family relationship? Please circle the choice that best indicates the extent of your satisfaction or dissatisfaction. You are welcome to consider whoever you like to include in 'your family'.

	Very Dissatisfied	Somewhat Dissatisfied	Generally Satisfied	Very Satisfied	Extremely Satisfied
The degree of closeness between family members	1	2	3	4	5
Your family's ability to cope with stress	1	2	3	4	5
Your family's ability to be flexible	1	2	3	4	5
Your family's ability to share positive experiences	1	2	3	4	5
The quality of communication between family members	1	2	3	4	5
Your family's ability to resolve conflicts	1	2	3	4	5
The amount of time you spend together as a family	1	2	3	4	5
The way problems are discussed	1	2	3	4	5

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Family Satisfaction Scale, D Olson © Life Innovations 2006)

1. What does the term wellbeing mean to you? (Prompt: How would you describe the concept of wellbeing to someone else?)

[illegible]

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3. In what way, if any, does the care of your vascular access contribute to your wellbeing?

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4. Drawing on your thoughts of wellbeing, please write about an incident when someone from your health care team helped you achieve a level of wellbeing that you were happy with. Include, if you can, what they did to help you achieve this level of well-being.

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5. Drawing on your thoughts of wellbeing, please write about an incident when your family helped you achieve a level of wellbeing that you were happy with. Include, if you can, what your family did to help achieve this level of wellbeing.

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6. What do you think you would have liked to have been told about your vascular access care at an earlier time? Please include why would this have been important to you?

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7. What values do you hold that are important to you and your health care?

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***Thank you for completing these questions!***

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## Appendix 8...*Site specific open questions for family members or carers*

Open Questions for family members or careers of people who experience haemodialysis treatment.

In these questions we are using the words 'your friend or loved one' to refer to the person who experiences haemodialysis treatment that you know:

1. What does wellbeing for 'your friend or loved one' mean to you? (Prompt: How would you describe the concept of their wellbeing to someone else?)

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2. What sort of things, if any, do you do to help 'your friend or loved one' achieve a level of wellbeing with which they are satisfied? Please write about an incident that best illustrates what things you do to improve wellbeing. (Prompt: Can you provide some examples from what you did in the last 7 days?)

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Site Specific Open Questions for Family Members or Carers



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3. Drawing on your thoughts of wellbeing, please write about an incident when someone from the health care team helped 'your friend or loved one' achieve a higher level of wellbeing. Include, if you can, what they did to help achieve this level of wellbeing.

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*Thank you for completing these questions!*

## **Appendix 9...*Site specific open questions for healthcare professionals***

Open Questions for health care professionals:

1. How would you describe the concept of wellbeing to a person who experiences haemodialysis treatment?

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2. What sort of things, if any, do you do to help people who experience haemodialysis treatment achieve a level of wellbeing with which you believe they are satisfied? Please write about an incident that best illustrates what things you do. (Prompt: Can you provide some examples from what you did in the last 7 days?)

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Site Specific Open Questions for Healthcare professionals

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3. In what way, if any, do you think vascular access care contributes towards patient's wellbeing?

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4. In what way, if any, does the health care team influence patient's wellbeing?

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5. Drawing on your thoughts of wellbeing, please write an incident when someone from the health care team helped a person who experience haemodialysis treatment or their family achieve a level of wellbeing that they were happy with. Include, if you can, what they did to help achieve this level of wellbeing.

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***Thank you for completing these questions!***

## Appendix 10... Authorisation from the SWSLHD director of Renal Services as delegate of that site



Health  
South Western Sydney  
Local Health District



SWSLHD RENAL SERVICE  
LIVERPOOL HOSPITAL

South Western Sydney Local Health District

**RENAL UNIT**  
NEW CLINICAL BUILDING  
LEVEL1 CLINIC G  
RECEPTION POINT 133

**MAILING ADDRESS**  
RENAL UNIT  
LOCKED BAG 7103  
LIVERPOOL BC NSW 1871

**PHONE: 8738-3708 - FAX: 8738-3718**

REF: MS/PTS

Debra Cowan  
Research Candidate  
University of Tasmania  
School of Nursing and Midwifery  
C/- 135 Watkins Rd Wangi Wangi  
NSW 2267

28 March 2013

### Re: Approval to proceed with Research Project.

Dear Debi,

I met with both yourself and Associate Professor Josephine Chow on Thursday, 22 March, to discuss your research topic on 'What bio-ecological factors influence the care of patient's vascular access for haemodialysis treatment'? As you have described, your research aim is to 'Enhance patient vascular access (VA) care experience through the development of VA management guidelines' with the following objectives:

- 1) Review current clinical management of patients VA requiring haemodialysis in a satellite haemodialysis unit.
- 2) Understand the patient's experience during management of their VA for haemodialysis in a satellite haemodialysis unit.
- 3) Review current guidelines and available literature related to clinical management of VA for patients requiring haemodialysis in a satellite unit and extract recommendations.
- 4) Discuss current evidence with experts, clinicians, patients and carers to gain consensus and develop agreed evidence statements for clinical practice guidelines.

I write to provide my support and approval for you to proceed with the distribution of surveys to clinicians, patients, families and carers of the XXXX Satellite Dialysis Unit.

My requirements being registration of your research with the Liverpool Renal Clinical Research Centre, Liverpool Hospital and providing myself with a report of the results of this project. Please have A/Prof. Chow arrange your introduction to the Nurse Unit Manager and arrange for the appropriate hospital clearance. I have copied my letter of approval to your University Higher Degree supervisors being Dr Lindsay Smith PhD Graduate Research Coordinator and Associate Professor Josephine Chow. It is a pleasure to support this research project and to be working with you once again.

Yours sincerely,

**Dr Michael G Suranyi MBBS FRACP PhD**

Conjoint Professor, UWS  
Conjoint Associate Professor, UNSW  
SWSLHD Director of Renal Services

cc Josephine Chow

## Appendix 11...Human Research Ethics Committee (Tasmania) Network

Office of Research Services  
University of Tasmania  
Private Bag 1  
Hobart Tasmania 7001  
Telephone + 61 3 6226 7479  
Facsimile + 61 3 6226 7148  
Email Human.Ethics@utas.edu.au  
www.research.utas.edu.au/human\_ethics/

HUMAN  
RESEARCH  
ETHICS  
COMMITTEE  
(TASMANIA)  
NETWORK



31 October 2013

Dr Lindsay Smith  
C/- Nursing and Midwifery

*Sent via email*

Dear Dr Smith

**REF NO:** H0013590  
**TITLE:** Vascular access management for patients requiring  
haemodialysis in a satellite haemodialysis unit clinical setting

Document	Version	Date
Application Form – Low Risk	-	-
Professor Michael Suranyi Letter of Support	-	28 Mar 2013
Participant Information Sheet	1.0	10 Oct 2013
Full Survey for Patients – Your health and Wellbeing	1.0	10 Oct 2013
Open Questions for Family Members or Careers	1.0	10 Oct 2013
Open Questions for Health Care Professionals	1.0	10 Oct 2013

The Tasmanian Health and Medical Human Research Ethics Committee considered and approved the above documentation on **29 October 2013** to be conducted at the following site(s):

South Western Sydney Local Health District

Please ensure that all investigators involved with this project have cited the approved versions of the documents listed within this letter and use only these versions in conducting this research project.

This approval constitutes ethical clearance by the Health and Medical HREC. The decision and authority to commence the associated research may be dependent on factors beyond the remit of the ethics review process. For example, your research may need ethics clearance from other organisations or review by your research governance coordinator or Head of Department. It is your responsibility to find out if the approvals of other bodies or authorities are required. It is recommended that the proposed research should not commence until you have satisfied these requirements.

All committees operating under the Human Research Ethics Committee (Tasmania) Network are registered and required to comply with the *National Statement on the Ethical Conduct in Human Research* (NHMRC 2007 updated 2009).



Therefore, the Chief Investigator's responsibility is to ensure that:

- (1) The individual researcher's protocol complies with the HREC approved protocol.
- (2) Modifications to the protocol do not proceed until **approval** is obtained in writing from the HREC. Please note that all requests for changes to approved documents must include a version number and date when submitted for review by the HREC.
- (3) Section 5.5.3 of the National Statement states:  
Researchers have a significant responsibility in monitoring approved research as they are in the best position to observe any adverse events or unexpected outcomes. They should report such events or outcomes promptly to the relevant institution/s and ethical review body/ies and take prompt steps to deal with any unexpected risks.  
The appropriate forms for reporting such events in relation to clinical and non-clinical trials and innovations can be located at the website below. All adverse events must be reported regardless of whether or not the event, in your opinion, is a direct effect of the therapeutic goods being tested.  
[http://www.research.utas.edu.au/human\\_ethics/medical\\_forms.htm](http://www.research.utas.edu.au/human_ethics/medical_forms.htm)
- (4) All research participants must be provided with the current Patient Information Sheet and Consent Form, unless otherwise approved by the Committee.
- (5) The Committee is notified if any investigators are added to, or cease involvement with, the project.
- (6) This study has approval for 4 years contingent upon annual review. A *Progress Report* is to be provided on the anniversary date of your approval. Your first report is due **29 October 2014**. You will be sent a courtesy reminder closer to this due date.
- (7) A *Final Report* and a copy of the published material, either in full or abstract, must be provided at the end of the project.

Should you have any queries please do not hesitate to contact me on (03) 6226 2764.

Yours sincerely

**Heather Vail**  
Ethics Administrator  
Office of Research Services  
Email: [Heather.vail@utas.edu.au](mailto:Heather.vail@utas.edu.au)  
University of Tasmania  
Private Bag 01 Hobart Tas 7001

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## Appendix 12... South Western Sydney Local Health Research and Ethics Office



**Health**  
South Western Sydney  
Local Health District

**Research and Ethics Office**

**Leadership • Quality • Governance**

Locked Bag 7103, LIVERPOOL BC, NSW, 1871

Phone: 02 8738 8304

Facsimile: 02 8738 8310

<http://www.sswahs.nsw.gov.au/swslhd/ethics/default.html>

26<sup>th</sup> March 2014

Dr Lindsay Smith  
School of Nursing and Midwifery  
University of Tasmania  
Locked Bag 1322  
Launceston TAS 7250

Dear Dr Smith,

**\*\*\*THIS LETTER CONSTITUTES ETHICAL APPROVAL ONLY. THIS RESEARCH PROJECT MUST NOT COMMENCE AT A SITE UNTIL SEPARATE AUTHORISATION FROM THE CHIEF EXECUTIVE OR DELEGATE OF THAT SITE HAS BEEN OBTAINED.\*\*\***

**Project Title:** Vascular access management for patients requiring haemodialysis in a satellite haemodialysis unit clinical setting.  
**HREC Reference:** HREC/14/LPOOL/48  
**SSA Reference:** SSA/14/LPOOL/49  
**Local Project Number:** 14/026

Thank you for your response dated 19<sup>th</sup> March 2014 to our request for further information dated 17<sup>th</sup> February 2014. This Human Research Ethics Committee is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Research Involving Humans* and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.

I am pleased to advise that the Committee has granted ethical approval of the above project.

The following documentation has been reviewed and approved:

Document	Version	Date
National Ethics Application Form	AU/1/D0B513	22/11/2013
Research Plan	1.0	26/03/2013
MASTER Participant Information Sheet (Patients)	1.0	10/10/2013
MASTER Participant Information Sheet (Family Members or Carers)	1.0	10/10/2013
MASTER Participant Information Sheet (Healthcare Professionals)	1.0	10/10/2013
Your Health and Well-Being	1.0	10/10/2013
Open Questions for Family Members or Carers	1.0	10/10/2013
Open Questions for Healthcare Professionals	1.0	10/10/2013
Letter of Support from Professor Suranyi	Nil	28/03/2013
University of Tasmania Human Research Ethics Committee Approval Letter	Nil	31/10/2013

Page 1 of 3



**Please ensure for all future documents submitted for review include a document version number, document date and page numbering.**

Monitoring Requirements:  
(National Statement Chapters 2.1 and 5.5)

- The Committee has classified this project as:

**Low Risk**

- Monitoring required for this study will be:
  - Submission of Annual Progress Reports with the first report due **26 March 2015 and annually thereafter for the duration of the approval period**

Approval has been granted for the following site(s):

- Hospital

Please note the following conditions of approval:

- **Insert Local Project Number 14/026 at the end of the complaints paragraph**
  - Please note the Office does not require a copy of the updated Participant Information Sheet and Consent Form. Please amend these before issuing to Participants
1. The Principal Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including:
    - any serious or unexpected adverse events; and
    - unforeseen events that might affect continued ethical acceptability of the project.
  2. The Principal Investigator will report proposed changes to the research protocol, conduct of the research, or length of HREC approval to the HREC in the specified format, for review. For multi-centre studies, the Chief Investigator should submit to the Lead HREC and then send the amendment approval letter to the investigators at each sites so that they can notify their Research Governance Officer.
  3. The Principal Investigator will inform the HREC, giving reasons, if the project is discontinued before the expected date of completion.
  4. The Principal Investigator will provide an annual report to the HREC and at completion of the study in the specified format.
  5. The Principal Investigator must reassure participants about confidentiality of the data.
  6. Proposed changes to the personnel involved in the study are submitted to the HREC accompanied by a CV where applicable.

HREC approval is valid for (5) years. If the study is ongoing at the conclusion of the five year approval period, a full resubmission may be required. Ethics approval will continue during the re-approval process.

**Optional:** It is the responsibility of the sponsor or the principal (or co-ordinating) investigator to register this study on a publicly available online registry (eg Australian New Zealand Clinical Trials Registry [www.anzctr.org.au](http://www.anzctr.org.au) )

**The South Western Sydney Local Health District Human Research Ethics Committee has been accredited by the NSW Ministry of Health to provide single ethical and scientific review of research proposals conducted within the NSW public health system and Victorian and Queensland Public Health Organisations participating in the Mutual Acceptance Scheme.**

**You are reminded that this letter constitutes ethical approval only. This research project must not commence at a site until separate authorisation from the Chief Executive or delegate of that site has been obtained. It is your responsibility to forward a copy of this letter together with any approved documents as enumerated above, to all site investigators for submission to the site's Research Governance Officer.**

Should you have any queries about your project please contact **Merela Ghazal** on the telephone number listed above. The HREC Terms of Reference, Standard Operating Procedures, membership and standard forms are available from the SWSLHD website:

<http://www.sswahs.nsw.gov.au/swslhd/ethics/default.html>

Please quote the Local HREC reference **14/026** in all correspondence.

The HREC wishes you every success in your research

Yours faithfully



Professor Jeremy Wilson  
Chairperson, SWSLHD Human Research Ethics Committee

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This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research* (2007). The processes used by this HREC to review multi-centre research proposals have been certified by the National Health and Medical Research Council.

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9<sup>th</sup> April 2014

Dr Lindsay Smith  
School of Nursing and Midwifery  
University of Tasmania  
Locked Bag 1322  
Launceston TAS 7250

Dear Dr Smith,

**Project Title:** Vascular access management for patients requiring haemodialysis in a satellite haemodialysis unit clinical setting.  
**HREC Reference:** HREC/14/LPOOL/48  
**SSA Reference:** SSA/14/LPOOL/49  
**Local Project Number:** 14/026

\*\*\*SITE SPECIFIC AUTHORISATION\*\*\*

Thank you for your email correspondence received 4<sup>th</sup> April 2014 in response to our request for further information dated 27<sup>th</sup> March 2014.

I am pleased to inform you that the Chief Executive has granted authorisation for this study to take place at the following site(s):

- ☐ Hospital

The participant documents approved for use at this site are:

- **Participant Information Sheet (Patients)**, site specific, Version 1.0, dated 4<sup>th</sup> April 2014  
Based on Master Version 1.0, dated 10<sup>th</sup> October 2013
- **Participant Information Sheet (Family Members or Carers)**, site specific, Version 1.0, dated 4<sup>th</sup> April 2014  
Based on Master Version 1.0, dated 10<sup>th</sup> October 2013
- **Participant Information Sheet (Healthcare Professionals)**, site specific, Version 1.0, dated 4<sup>th</sup> April 2014  
Based on Master Version 1.0, dated 10<sup>th</sup> October 2013

**Note:** CV's for Dr Smith and associated investigators are not required to be submitted for future 2014 projects as there is now one on file.

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

- Insert Local Project Number 14/026 at the end of the SWSLHD complaints paragraph  
*\*Changes made to documentation do not need to be forwarded to the office. Please amend before issuing to participants.*

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, are copied to this office.
2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, are to be submitted to this office.
3. Please note that you are responsible for making the necessary arrangements (e.g. identity pass and vaccine compliance as per NSW Health Policy Directive PD2011\_005) for any researcher who is not employed by the South Western Sydney Local Health District and is conducting the research on-site.

Yours sincerely

Annamarie D'Souza  
Manager, Research and Ethics Office  
South Western Sydney Local Health District (SWSLHD)

**Appendix 13...PPCT model: 13 Concepts, texts and terms employed by each group**

*NB: The final column the four most frequently utilised by participants.*

Concept	Texts and Terms	Patient	Carer	Staff	Total	Frequent Term
Process:						
Comfort and acknowledge	Care / look after, intervene, resolve, cater for, accommodate / needs / flexibility, support, assist, help, encourage / reassure, communicate / converse / chat / talk / listen / interact / acknowledge / comfort / compassion / thoughtful / attentive / friendly / kind, safe / protected and belonging.	(n=90)	(n=26)	(n=56)	(n=152)	Help (n=43) Care/ look after (n=35) Support (n=25) Encourage (n=11) Comfort (n=6)

<b>Being loved</b>	Family, partner, husband, wife, daughter, son, sister, children / grandchildren and or friends (and as carers) including other patients and carers.	(n=21)	(n=8)	(n=11)	(n=40)	Family (n=37) Daughter (n=24) Carer (n=5) Grand/Children (n=3)
<b>Knowledge and rights</b>	Knowledge, inform, guidelines, safe practice, recommend, involve, sharing, told, advise, educate, learn, teach, instruct, addressed, discuss, explain, understand, rights, choice, options, beliefs, culture, values, preferences, decision making, refuse, consent and goals.	(n=19)	(n=0)	(n=21)	(n=40)	Educate (n=13) Advise/ advice (n=10) Inform (n=9) Explain (n=8)



<b>Hygiene</b>	Clean, wash, hygiene and sterile.	(n=15)	(n=1)	(n=2)	(n=18)	Clean (n=10) Wash (n=4) Hygiene (n=2) Sterile (n=2)
<b>Person:</b>						
<b>Normal</b>	Physical, fit, function, normal, activities of daily living (ADLs), participating, exercise, walk, shopping, work, hobby and holiday / visiting / socializing.	(n=78)	(n=20)	(n=32)	(n=130)	Physical (n=28) Exercise (n=14) Walk (n=7) Shopping (n=6)
<b>Independence and self-care</b>	Responsible, independence, wealth, financial status, take / self-care, monitor / assess, change / adapt, blood, eating, diet, fluid, restrictions, medications, haemo / dialysis, treatment, IBW clearance/ uremic and waste.	(n=52)	(n=14)	(n=63)	(n=129)	Treatment (n=33) Haemo/dialysis (n=29) Diet (n=14) Blood (n=7) Medication (n=7)



<b>Happy</b>	Happy, well, alive, enjoy, cheerful, humour, laugh, alright, settled, thankful, comfortable, quality of life (QOL), sleep, faith, spiritually, at peace, content, confident, satisfied, attitude, mindset, mood, spirits, accepting, dignity, integrity, trust, privacy, respected, being heard, feeling of worth, feel special and loved.	(n=81)	(n=18)	(n=27)	(n=126)	Happy (n=39) Comfortable (n=8) Well (n=8) Attitude (n=4)
<b>Mental and emotional</b>	Mental, mind, psychologically, cope, stressed, anxious, emotional, feel sad, unhappy, angry, depressed, feel different,	(n=36)	(n=13)	(n=21)	(n=7)0	Emotional (n=19) Mental (n=13) Concern (n=8) Cope (n=7)

	alone, unsafe, going through, concerned and need.					
<b>Getting sick</b>	Disease, pain / hurt, sick / unhealthy, unwell, symptoms such as cramping, poor appetite, nausea / vomiting and breathless / SOB, dizziness, tired, old, limited, pass away / extinct / death.	(n=16)	(n=9)	(n=13)	(n=49)	Unhealthy/sick/unwell (n=7) Pain/hurt (n=7) Disease (n=5) Short of breath/SOB (n=5)
<b>Life-line</b>	Vascular/access, AVF / fistula / lifeline / veins, needle, complications, clot, aneurism, infection/ sepsis, injury, hospitalisation and intervention / surgery.	(n=38)	(n=1)	(n=27)	(n=67)	Vascular/access (n=20) AVF/fistula/lifeline/vein (n=19) Infection/sepsis (n=13) Clot (n=7)
<b>Context:</b>						

<b>The team</b>	Healthcare staff, team, doctors GP, specialist, registrar, nurses, students, dietician, social worker, psychologist, manager / NUM, nurses, students, staff, resources and equipment.	(n=33)	(n=1)	(n=7)	(n=41)	Staff (n=17)  Team (n=11)  Nurses (n=9)  Doctors (n=5)
<b>Feeling safe</b>	Dialysis / centre / hospital (SHDU) and home (environment / place).	(n=16)	(n=5)	(n=3)	(n=24)	Dialysis / hospital (n=15)  Home (n=8)
<b>Time:</b>						
<b>Time</b>	A period of time such as hours, months, before, after, now and then, sometimes, at times, other times, all the time, long time, regular, always, timely, prompt, quality time, my time, spending time and isolated time	(n=29)	(n=3)	(n=8)	(n=40)	Always (n=11)  Before (n=7)  After (n=7)  Regular (n=4)

Appendix 14...Non-parametric Correlations

			Patient Empowerment Scale	Family Strengths Attributes Scale - Healthcare professionals	Family Satisfaction Scale	SF-36v2 - Physical Component Summary	SF-36v2 - Mental Component Summary
Kendall's tau_b	Patient Empowerment Scale	Correlation Coefficient	1.000	.292*	.227	.336**	.136
		Sig. (1-tailed)	.	.018	.052	.008	.161
		N	29	29	29	28	29
	Family Strengths Attributes Scale - Healthcare professionals	Correlation Coefficient	.292*	1.000	.616**	.187	.338**
		Sig. (1-tailed)	.018	.	.000	.085	.006
		N	29	29	29	28	29
	Family Satisfaction Scale	Correlation Coefficient	.227	.616**	1.000	.087	.422**
		Sig. (1-tailed)	.052	.000	.	.263	.001
		N	29	29	29	28	29
	SF-36v2 - Physical Component Summary	Correlation Coefficient	.336**	.187	.087	1.000	.108
		Sig. (1-tailed)	.008	.085	.263	.	.201
		N	28	28	28	30	30
	SF-36v2 - Mental Component Summary	Correlation Coefficient	.136	.338**	.422**	.108	1.000
		Sig. (1-tailed)	.161	.006	.001	.201	.
		N	29	29	29	30	31

\*\* . Correlation is significant at the 0.01 level (1-tailed).

\* . Correlation is significant at the 0.05 level (1-tailed).

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